DOCUMENT RESUME

ED 398 696 EC 304 988

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TITLE	Promoting Self-Advocacy and Facilitating Friendships and Socialization Skills for Individuals with Disabilities. Module Three. Facilitator's Edition [and] Student's Edition. Strategies for Paraprofessionals Who Support Individuals with Disabilities Series.
INSTITUTION	Hutchinson Technical Coll., MN.; Minnesota State Board of Technical Colleges, St. Paul.; Minnesota State Dept. of Education, St. Paul.; Minnesota Univ., Minneapolis. Inst. on Community Integration.
SPONS AGENCY	Administration on Developmental Disabilities (DHHS), Washington, D.C.; Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE	Nov 95
CONTRACT	84029F20009; 90000302
NOTE	387p.; For other modules, see EC 304 986-992.
AVAILABLE FROM	University of Minnesota, The Institute on Community Integration (UAP), 150 Pillsbury Drive, S.E., Minneapolis, MN 55455 ($25 facilitator edition; $15 student edition).
PUB TYPE	Guides - Classroom Use - Teaching Guides (For Teacher) (052) -- Guides - Classroom Use - Instructional Materials (For Learner) (051)
EDRS PRICE	MF01/PC16 Plus Postage.
DESCRIPTORS	Advocacy; Assertiveness; Curriculum Guides; *Disabilities; Educational Legislation; Elementary Secondary Education; Federal Legislation; *Friendship; Inservice Education; *Interpersonal Competence; Laws; Lesson Plans; *Paraprofessional School Personnel; Postsecondary Education; School Aides; Self Determination; *Socialization; *Staff Development; Staff Role; Student Empowerment; Teacher Aides
IDENTIFIERS	*Self Advocacy

ABSTRACT

The third in a series of federally supported modules for training paraprofessional school personnel who work with students with disabilities, this module focuses on training self-advocacy skills, facilitating friendships, and developing socialization skills for individuals with disabilities. Both a facilitator's edition and a student's edition are provided. Chapter 1 provides an introduction to self-advocacy. Chapter 2 focuses on promoting self-advocacy and the art of negotiation. Chapter 3 discusses the characteristics of a skillful self-advocate. The rights of people with disabilities and applicable federal legislation are discussed in Chapter 4. Chapter 5 provides information on promoting self-advocacy in individuals with disabilities. Chapter 6 discusses facilitating friendships and socialization skills. Issues in developing friendships for individuals with disabilities are reviewed in Chapter 7. Chapters 8 and 9 discuss the development of social networks and ways to facilitate friendships. Planning for the future is covered in Chapter 10. Fourteen appendices are attached, including fact sheets on federal legislation, a conversation start-up kit, and articles on self-advocacy. The facilitator's edition offers learning activities and information sheets to be used as transparencies. (Contains 24 references.) (CR)

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Module Three

Promoting Self-Advocacy and Facilitating Friendships and Socialization Skills for Individuals with Disabilities

Facilitator's Edition

Prepared by
Institute on Community Integration (UAP)

UNIVERSITY OF MINNESOTA
The College of Education
and Human Development

EC 304988

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Published November, 1995.

The paraprofessional training module *Promoting Self-Advocacy & Facilitating Friendships and Socialization Skills*, in the series *Strategies for Paraprofessionals Who Support Individuals with Disabilities*, was prepared at the Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota.

The development of these materials was supported in part through the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), grant #84029F20009 and the Administration on Developmental Disabilities (ADD), U.S. Department of Health and Human Services, grant #90000302. The opinions expressed herein are those of the authors and do not necessarily reflect the position of the U.S. Department of Education or the U.S. Department of Health and Human Services. This project is a collaborative effort between the Institute on Community Integration, Hutchinson Technical College, the Minnesota Department of Education, and the Minnesota State Board of Technical Colleges.

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Acknowledgments

The Advisory Committee of the Federal Paraprofessional Training Grant offered suggestions and support for the development of this module. The Institute on Community Integration at the University of Minnesota and the Hutchinson Technical College, working in collaboration on this project, would like to acknowledge and thank the members of the Advisory Committee for their efforts. The committee members are:

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Facilitator's Outline

About the Facilitator's Outline

This training module contains a facilitator's outline designed to assist instructors as they plan and prepare to teach the material contained in this module. The outline provides overviews of each chapter which include:

- Chapter goals to be accomplished by students.
- Topics to be covered in each section.
- Discussion questions to facilitate lectures and discussions and activities to be completed by students both in and out of class.

These items are the same as those appearing in the outside margins of the facilitator's edition of this module. The discussion and activity notes, and answers to activity questions, appear in the facilitator's edition only – they do not appear in the students' edition. The text, however, is the same in both. In some cases, the discussions and activities may have been abbreviated in this outline, but provide the same basic information as it appears within the context of the chapter.

This outline can be used when planning lessons. It's a good idea to read through the outline before using it for instruction in order to know what to expect and get a better sense of how the material is tied together.

The content of this module is based on a training series piloted in 1994 by Hutchinson Technical College in Hutchinson, Minnesota. Because of this, many references are specific to Minnesota's school and social service systems. We encourage instructors located in other states to replace the Minnesota-specific information with information more relevant to their state. We hope that facilitators will add their own experiences and stories to make this material "come alive".

Chapter 1
Introduction to Self-Advocacy

Chapter Goals

Upon completing this chapter, students should be able to:

- Define *self-advocacy, empowerment,* and *interdependence.*
- Recognize their role as a paraprofessional in the self-advocacy process.
- Demonstrate an ability to promote both self-advocacy and empowerment.

Section 1: Self Advocacy

Activity 1

In addition to reading the descriptions of self-advocacy, empowerment, and interdependence, have students take turns reading aloud sentences in order from the handout entitled "The Dignity of Risk" found in Appendix A. Afterwards, ask students to express their feelings about the statements. Do they feel they are accurate statements about the limitations placed on people with disabilities by society? Do they think those limitations have merit or are fair. Allow the feelings of the group to be expressed, relating the ideas expressed to the importance of the need for individuals to have the right and ability to set their own course.

Activity 2

An important aspect of self-advocacy is the family's involvement. As background information and "food" for discussion, have the students read the article "Family Empowerment" from the Beach Center on Families and Disability newsletter found in Appendix B. Encourage discussion about the issues related to family involvement and empowerment. How does this affect the working relationship of the paraprofessional who is often the "go between" between parents and other staff because the paraprofessional is the one who may have the most physical contact with family members on a daily basis? Also discuss the role of the paraprofessional in encouraging the family to let their member make more decisions and choices as the individual moves toward/into adulthood.

Activity 3

Have students read the article entitled "Empowerment: Dependence versus Independence" by Frank G. Bowe, Ph.D. from the *OSERS News In Print* newsletter found in Appendix C. Discuss the article with the class in terms of its implications on self-advocacy now with the Americans with Disabilities Act legislation.

Activity 4

Ask the students to do this at the beginning of class. Give them about 5–8 minutes to complete circling. Then ask the group to list behaviors they chose. Write them down. Which behaviors are most prevalent? Ask the students which behaviors they feel are most supportive of self-determination behaviors. Which behaviors do they feel don't promote self-determination? Make a list. Ask the students to, for their own records only, state behaviors they would like to improve upon in the future that would promote self-advocacy.

Activity 5

Have two students read the "Shifting Patterns, Beliefs and Attitudes" chart out loud. Have one student read "from" statements and alternate with another student reading "to" statements. After they finish, ask the group their feeling or reaction to the "from" phrases versus the "to" phrases. Discuss any unknown phrases or terms. Do they have an emotional response to one over the other? Do they characterize the individuals they work with or will work with using more statements found in the "from" side more than the "to" side? Ask them to think about going to work in a new setting where the treatment of the individuals with disabilities is characterized more by the "from" column than the "to" column. How would they react to this environment? What steps could/would they make to change the environment? Allow time for good discussion on this topic.

Chapter 2

Promoting Self-Advocacy

Chapter Goals

Upon completing this chapter, students should be able to:

- Identify ways they can encourage self-advocacy.
- Recognize their attitude about self-advocacy.
- Define ways people self-advocate.
- Demonstrate an ability to respond to self-advocacy.
- Identify steps they can use to help people learn to negotiate.

Section 1: Encouraging Self-Advocacy

Activity 1

Have students read and discuss this section along with the articles "Advocacy: Noun, Verb, Adjective or Profanity?" in Appendix D, and "Confessions of a Professional" in Appendix E. Ask students to discuss what role the paraprofessional may have as an advocate for an individual or family. Is this informal or formal advocacy? What should it be? Ask the students to share personal experiences as advocates. Discuss the five lessons learned by the professional and how they relate to the students' experiences. Discuss enabling attitudes – when they're appropriate and when they're not. Explain that helping individuals to become self-advocates is tricky business. On the one hand they need you and on the other hand you must "push them out of the nest". Make sure that students realize their role isn't to enable learned helplessness. Discuss this as a group.

Activity 2

Have the students complete the following scenario outside of the classroom. They should be prepared to discuss the process they applied to reach appropriate self-advocacy with the class upon completion.

Activity 3

Have students complete "Evaluating Your Attitude" following the instructions given. Then have them find a partner and compare their responses. After discussing with a partner, call the group together to discuss what, as a group, they feel are the essential attitudes and beliefs necessary to promote self-advocacy.

Activity 4

Go through this list and explain and discuss each question. Ask students to examine their behavior in the past and consider how they will or do work with individuals with disabilities. Since we must assume we all have biases to some extent, in what way do their biases show themselves? The above questions may draw out some of those biases. If they do, discuss with students what they can do to readjust their thinking to be more pro-active in behalf of individual's self-advocacy.

Activity 5

Discuss with students the importance of them being aware of such "cues" as these ten questions. Sometimes individuals won't act in a very demonstrative way, but still may have good skills to self-advocate and may be asking for help, but the paraprofessional may not recognize it. This can be so disappointing to the individual that it may discourage him or her from advocating in the future. Therefore, the paraprofessional must have a "trained ear" to listen for signs of self-advocating and encourage those signs. Discussing these questions can be one way of creating an awareness for paraprofessional.

Activity 6

Tell the students that these steps are equally appropriate for students or individuals in a work setting. These are steps that are intended to be used with situations as they arise on a daily basis. Detailed plans for self-advocacy will be included in the individualized program to be used on a regular basis.

Activity 7

Have students try the following situation in small groups, then share their responses with the class.

> **Situation:** A sixth grade student with a learning disability comes to you, the paraprofessional in the special ed resource room, and says she has to write a paper on the Civil War for history class. The girl has a severe writing disability and some organizational skills challenges. You have been helping her and working with the classroom teacher throughout the year. What solutions will the two of you identify?

Section 2: The Art of Negotiation

Activity 1

Have the students discuss the importance of clearly "training" individuals in negotiation skills as they help them prepare to advocate for themselves.

Activity 2

Have students read the seven situations from the "Basic Human Rights and Responsibilities" scenarios. Encourage students to notice how important it is to observe individual rights and responsibilities in the negotiation process. Have the students pick a partner and have them discuss their styles of negotiation and then share their observations with the rest of the class.

Chapter 3

What it Takes to Be a Successful Self-Advocate

Chapter Goals

Upon completing this chapter, students should be able to:

- Define the successful behaviors of a self-advocate.
- Identify passive, aggressive, and assertive behavior.
- Demonstrate effective self-advocacy techniques in difficult situations.
- Assist a person with disabilities to prepare for an individual planning meeting.
- Identify reasonable accommodations.

Section 1: Characteristics of a Successful Self-Advocate

Activity 1

Discuss the attributes of successful self-advocates. Have students add to the list. Discuss what they feel their role as a paraprofessional can and should be toward this success.

Activity 2

Have the students practice using the charts on pages 24 and 25 either with a partner from the class, an individual they are currently working with, a friend or family member, or on themselves. Tell students to be very specific in listing skills. What seems small and insignificant may lead to discovering a vital link to help the individual.

Activity 3

Passive, aggressive, and assertive behaviors were discussed in the first module in this series, *The Paraprofessional: An Introduction*. Referring back to that module may be appropriate here. Explain that it's important for the paraprofessional to have a working understanding of the difference between these three behaviors because they have a daily influence on how the individual learns these behaviors and responds to situations in an assertive, appropriate manner.

Activity 4

These are suggestions for paraprofessionals to use with individuals who are self-advocating. Everyone is bound to run into the four C's eventually: *complaints, criticism, conflict, and compliments.*

Individuals need to realize that each of these have potential problems and rewards. Being able to handle conflict and compliments is a skill that is part of independent living. Tell students to discuss these four C's with the people they will work with and help them understand the meaning of each. Help students take an active role and address complaints, criticism, conflict, and compliments with people with whom they work in the natural setting of their daily environment.

Activity 5

Have the students fill this out with a partner in class and then discuss it as a group. What are the types of accommodations the students decided upon for this student? What others might be needed on the job? Have students go through this process with the comments on their own strengths and weaknesses charts. Explain to the students how important it is to take time with individuals to prepare them for meetings so they will be able to responsibly advocate for themselves.

Activity 6

Review and discuss these steps to self-directed individual planning meetings with the class.

Activity 7

Explain to participants what an important role they can play in helping individuals decide on a daily basis what to ask for in order to receive the accommodations needed to be successful in all environments. Have them share experiences where they have helped individuals determine their needs and then ask for them appropriately. Explain that one of the pitfalls for paraprofessionals here is knowing when to back out and let the individual take over for him- or herself. There's a very delicate balance that needs to be observed so the individual becomes accustomed to self-advocating as soon as possible. Explain to participants how important they are in helping individuals learn to make decisions about their needs and accommodations in various environments.

Activity 8

Have students read "Out of My Old Life and Into My New One" by Michael Kennedy, a young man with cerebral palsy, found in Appendix F. This article is meant to illustrate to students the determination of one man and what assertive self-advocacy can accomplish. Discuss Michael's situation and the examples of self-advocacy illustrated in the article. Have the students share situations that may be similar. After students have read the article, have them discuss the following topics with each other. Have any of the students had similar situations with individuals like Michael? Ask students to imagine what Michael's life was like before he attained the level of independence he was capable of. What does this article say to paraprofessionals working with individuals with disabilities? What does it say to all of us about limitations we place on each other?

Activity 9

An optional activity at this point would be to have a panel discussion. Invite individuals in the area who have disabilities and have developed self-advocacy skills to come into class and discuss their experiences, both positive and negative, in this endeavor. Ask each panel member to prepare to give initial statements about their lives, their histories, and how they have become self-advocates. After these initial statements, have the students use the following questions to enhance discussion with the panel members. At the end of the discussion, thank the panel member and students for participating in the discussion. If you can gather a good panel together one time, ask their permission to videotape the discussion. This videotape can then be used at a later time with other students or for further discussion.

Chapter 4

Rights of People with Disabilities

Chapter Goals

Upon completing this chapter, you should be able to:

- Identify the rights of the self-advocate, the consumer rights statement, and the Resident Bill of Rights.
- Discuss the Americans with Disabilities Act, Section 504 of the Rehabilitation act of 1973, IDEA, and Part H of IDEA.
- Discuss the use of behavioral interventions.

Section 1: Individual Rights

Activity 1

Have the students read these three sets of rights. Explain that these are examples of basic human rights for which all people are entitled. Explain to the students that these are included in the module because sometimes people with disabilities are denied the basic rights of others on the basis of their disability. Explain that it's important to remember as a starting point that these are basic human rights for all. Have a discussion about these rights, especially the United Nations Universal Declaration of Human Rights and how those rights may be and have been denied individuals with disabilities.

Activity 2

Have students read and then discuss the various components of the "Residents' Bill of Rights". Tell students this is an example of the type of rights statements they should find or be given upon request in any residential setting. Use this as another example to illustrate the rights that are mandated and provided for individuals with disabilities.

Section 2: Disability-Related Laws

Activity 1

Have students read the Fact Sheet on ADA, found in Appendix G, and discuss the main points of the law. Have students discuss the impact the law has had on Roberta L. Juarez based on her article "The Kindness of Others" in Appendix H.

Activity 2

Read and discuss the Section 504 Fact Sheet found in Appendix I and other information with students. Remind students how important it is for the individuals with whom they work to understand their rights under Section 504 and other laws.

Activity 3

Discuss the rights of parents under IDEA. Ask for student input. Relate the knowledge of these laws and their importance to the ability of individuals and their parents to advocate.

Activity 4

Because so many paraprofessionals in schools deal with behavioral challenges, this section should lend itself to discussion. Encourage students to discuss the pros and cons of this ruling and to relate personal experiences. Remind students that the discipline decisions for students they work with should be directed from their supervisor.

Chapter 5
Making a Commitment to Self-Advocacy

Chapter Goals

Upon completing this chapter, students should be able to:

- Describe ways they and others can encourage and promote self-advocacy for individuals with disabilities.
- Describe ways the community can encourage self-advocacy for individuals with disabilities.

Section 1: Promoting Self-Advocacy in Individuals with Whom You Work

Activity 1

Participants can use these tips as ways to promote and encourage independence, empowerment and self-advocacy in their setting. Tell students that an atmosphere must be created where it's the norm to expect individuals to self-advocate. They can be a big part of that atmosphere by carefully nurturing individuals toward their capacity and their own level of independence and then sharing those successes with other staff members and administration. Have students discuss ways they can promote independence.

Activity 2

Discuss these points with the class as a lead-in to the activity called "Promoting Self-Advocacy".

Activity 3

Have students complete this as a homework assignment. If they aren't in a work setting yet, have them either brainstorm ideas they could use to promote self-advocacy or interview someone in their community that would have good ideas, such as a rehabilitation counselor, teacher, or a school counselor. Students should bring this form back to the next session filled out and then form small groups to discuss their ideas. Have each group share their ideas with the class. Make a master list of these ideas and give each student a copy for future reference.

Activity 4

Tell students that in their position as a paraprofessional, they can be very influential in encouraging individuals and their families to get involved in the change process and make their communities better for individuals with disabilities. Tell them these are some ways they can encourage action, but what are some others? Encourage discussion around these action steps.

Activity 5

Have the students read the article "Who Can Teach Change Better?" in Appendix J as another perspective of how and advocate can relate to individuals as an advisor, as well as an advocate. Ask them how they view themselves as paraprofessionals. Can they see their role as also one of advising individuals toward their own independence? Have students discuss this with a partner. What should their role be in advising?

Activity 6

Have students read the NICHCY newsletter on self-determination found in Appendix K.

Chapter 6

Facilitating Friendships & Socialization Skills

Chapter Goals

Upon completing this chapter, students should be able to:

- Identify the philosophy in facilitating friendships for individuals with disabilities.
- Describe the three kinds of activities that help people build connections with others: finding opportunities, interpretation, and accommodations.

Section 1: Facilitating Friendships and Socialization

Activity 1

This section serves as an introduction. It can be read independently and then discussed as a group. When discussing this, ask students what they think happens when one group is segregated from society. Ask them to share any experiences they might have had in facilitating friendships with individuals with disabilities.

Activity 2

Ask students to fill out this twelve point "Friendship Quotient" individually. If they have comments or feelings about any of the statements, ask them to write those under each statement. Then go through the questions, item by item with the entire group and ask for comments anyone has for each statement. Hopefully they will have strong feelings about integrated vs. segregated environments for socialization skill development. Encourage them to discuss their personal biases about friendship development between persons with disabilities and persons without disabilities. Tell the students in this module they will learn skills to facilitate persons in relationships so they can learn to develop healthy friendships in school work and in community settings.

Activity 3

Have the students break up into small groups and brainstorm what they would do in the following situations to facilitate friendships by: finding opportunities, interpretation, and accommodations. Have them meet for ten minutes in these groups and write down their answers. Then have the groups share and discuss their results with each other.

Chapter 7

Issues in Developing Friendships for Individuals with Disabilities

Chapter Goals

Upon completing this chapter, students should be able to:

- Understand the importance of community ties and friendships.
- Understand issues in developing and sustaining acquaintances, friendships, interests, and membership in the community.
- Understand issues surrounding being part of a family, having a partner, or being a good neighbor.

Section 2: Issues in Developing Friendships

Activity 1

Discuss with other ways to facilitate friendships. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Section 3: Issues in Developing Acquaintances

Activity 1

Discuss with the class other ways to facilitate acquaintances. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Section 4: Issues in Developing Membership

Activity 1

Discuss with the class other ways to facilitate membership. Write them down as the suggestions are given. Have students write them in the space for "other suggestions that work".

Section 5: Issues in "Keeping in Touch"

Activity 1

Discuss with the class other ways to facilitate "keeping in touch". Write them down as the suggestions are given. Have students write them in the space for "other suggestions that work".

Section 6: Issues in Being Part of a Family

Activity 1

Discuss with the class other ways to facilitate being part of a family. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Section 7: Issues in Having a Partner

Activity 1

Discuss with the class other ways to facilitate positive partnerships. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Section 8: Issues in Being a Good Neighbor

Activity 1

Discuss with the class other ways to facilitate good neighborhood relationships. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Chapter 8
Developing Social Networks

Chapter Goals

Upon completing this chapter, students should be able to:

- Identify your support system.
- Identify strategies to find out about neighborhood groups.
- Demonstrate the benefits people in a social network get from one another and give to one another.
- List ten considerations when building a relationship.
- Identify facilitator do's and don't's.

Section 1: Social Networks

Activity 1

Have students fill out the handout "Looking at My Support System" either as a homework assignment or in class. Have them discuss who in their own lives makes up their support system. Discuss this as a group. Tell students to use this activity to help prepare individuals they work with for the next activity.

Activity 2

Tell students you're going to walk through this next activity in the same way they could do it with individuals with whom they work. Say to students, "Who are the people in your life who are important to you? Start with yourself in the center ring. Fill in the names of people who are the most important to you in the next ring, the next level in the next ring, and so on, until the outer ring includes acquaintances or people who are on the periphery in your life. Notice the notches in each circle. Each notch is a place for a name of someone in that ring you would like to be in a closer ring. Write there name there. What can you do to work toward that with that person? How can you relate these ideas to helping individuals with disabilities you work with to work toward closer relationships?" Tell students they can use the second blank circle to do this same exercise with an individuals they're working with (or will in the future) who needs to improve his or her relationships with others.

Activity 3

Have the students look at and discuss the figures "I Get My Support from My Relationship with Others" and "My Personal Support Network". Discuss the circles that overlap and how relationships are all different from each other. Discuss how these could be used to help people with whom students will work. As an out of class assignment, have students work through this worksheet in one of two ways, depending on the nature of the class. If most students are currently working, have them do this exercise with an individuals with whom they work. If not, have them do the activity with a friend or neighbor.

Activity 4

Have the students complete this chart using themselves. Tell them this is also an activity they could use with individuals to help them discover others in their lives they'd like to know better.

Activity 5

Go through this list with the class and discuss how important it is for paraprofessionals to have a network and supply of ideas when helping individuals learn how to network and become involved in their communities since most individuals won't have many ideas of their own. Ask students to add to the list, from their experience.

Activity 6

All these reasons for a social network should be discussed. Discuss what life would be like for the students if they had no, or very little, social network. Then discuss the difficulties many persons with disabilities have in relation to these difficulties. Explain that often individuals with disabilities don't have as many opportunities to tap into sources for building social networks. This creates feelings of uselessness and isolation. This makes it even more important for the paraprofessional to work as a facilitator for friendship and social network building. Everyone of the above avenues for social network building can be opportunities for paraprofessionals to help individuals tap into systems to make friends.

Have students read and discuss "Making Contributions" in Appendix L. Discuss the ideas for students to help encourage individuals to get involved in neighborhood & community activities to help create and develop their own social network.

Activity 7

Have the students break up into small groups and "pretend" to be running a weekly staffing where they're discussing the social situation in the following role-play. Have someone record the discussion. The group "team meeting" should come up with some IEP/IHP long-term objectives for this situation and some short-term, or weekly goals for which to strive.

Activity 8

Explain to students that the importance of understanding this list of "Ten Considerations for Building Relationships" is in the fact that all relationships with all people follow this pattern to one degree or another. When working to facilitate friendships for and with persons with disabilities it's especially important to remember that there might be some difficulty in some of these considerations. Some individuals may not understand the subtitles addressed here in establishing relationships and may need to be taught these ten steps very deliberately as a means to help facilitate relationships. Paraprofessionals should discuss these ten points as a group and brainstorm ways they would "teach" these tips to individuals with whom they work.

Activity 9

Hold a discussion with students about the do's and don't's of facilitating friendships. Emphasize that there's a delicate balance between being proactive and taking over the relationship development and the paraprofessional needs to support the activity but not force friendships.

Chapter 9
Facilitating Friendships

Chapter Goals

Upon completing this chapter, students should be able to:

- Identify strategies that could assist people with disabilities to start friendships.
- Identify activities to facilitate friendships.

Section 1: How to Facilitate Friendships

Activity 1

Ask students to give examples for each of the eight steps to facilitating friendships from work or personal experiences. Discuss these as a group. Ask students to discuss these questions: What's the most difficult part of facilitating friendships? How do you think you'll know when to back out and let the people handle the friendship on their own? How can you "find opportunities" without getting overbearing? How can you accommodate situations without being patronizing?

Activity 2

Have students brainstorm in small groups and come up with additional activity ideas, then have each group share their ideas with the whole group.

Activity 3

Paraprofessionals may want to look at the ideas in the "Conversation Start-Up Kit" found in Appendix M as ideas to use to role play situations with individuals to help them get started in a conversation. Paraprofessionals can practice ideas for starting conversations with individuals in various circumstances as a way to initiate contact that can lead to relationships.

Activity 4

Additional resource ideas to help facilitate friendships: Students should read and discuss the ideas in the handouts "A Catalogue of Ideas", "Doing Things Together", and "Community Resources" located in Appendix N.

Chapter 10

Planning for the Future

Chapter Goals

Upon completing this chapter, students should be able to:

- Describe MAPS and Personal Futures Planning.
- Identify do's and don't's of person-centered planning.

Section 1: Promoting Friendships and Self-Advocacy Through Futures Planning

Activity 1

Tell the students there are many strategies used for planning the future with individuals with disabilities. These are just two, but they illustrate the importance of individual self-advocacy.

Activity 2

Have students read and discuss the seven steps of Personal Futures Planning. Discuss the implications of Personal Futures Planning on the IEP/IHP process. This is required in the transition planning process. Paraprofessionals can be instrumental in gathering this information and sharing it at the individual's planning meeting. Discuss the Personal Futures Planning process and the impact it can have on the process of empowering individuals to be their own best advocates. How can Personal Futures Planning effect the individual's ability to develop relationships?

Activity 3

Stress the following do's and don'ts about futures planning and looking at the abilities and capacities of the individual.

Activity 4

To become more familiar with the process of futures planning, have students read the three following scenarios. Although these three situations deal with adult individuals, stress that futures planning can be done at all ages. After students read the scenarios, discuss the benefits that the futures planning brought to the lives of Gordon, Cindy, and Helen.

Introduction

An Introduction to the Series

This series should be useful to paraprofessionals and paraeducators in education as well as direct service staff in community agencies in preparing for a career or in upgrading skills while already employed. Skills needed by individuals working under a variety of titles are often similar. Our focus is on those individuals working in education, but most of the information contained in this series is appropriate for others; please feel free to adapt it where needed.

The Need for Today's Paraprofessionals

The need for paraprofessionals to work with persons who have disabilities has been growing in recent years. Increasing numbers of persons with a range of disabilities are now living in small residential settings in our communities, attending regular classes in neighborhood schools, holding jobs in local businesses, and participating in community recreation and social activities. There is a great need for paraprofessionals to provide the services and supports these individual need for community living.

By employing paraprofessionals, services for persons with disabilities are able to expand and improve the quality of assistance they provide. Some of the benefits paraprofessionals offer service agencies and consumers are:

- Expanded learning opportunities for persons with disabilities.
- More individualized attention and instruction.
- Increased opportunities for individuals with disabilities to observe and learn appropriate behaviors.
- Increased planning time for educators, supervisors, and others.
- Improved staff morale.
- Better monitoring and evaluation of persons with disabilities.
- Greater consistency in services.
- Improved parent-school relationships.
- Greater involvement of persons with disabilities in education and other settings in the community at large.
- Transportation assistance for individuals with disabilities.
- Vocational skill development for individuals with disabilities.

The Role of Today's Paraprofessional

Paraprofessionals who work with individuals with disabilities have a variety of roles and definitions, depending on the environment in which they work. The Minnesota Department of Education (MN 3525.0200, Subp. 9b) definition states that a program assistant or pupil support assistant provides services to students only under the direct guidance and direction of a regular or special education teacher or related provider, and those services must be:

- To enhance the instruction provided by the teacher or related staff in academic instruction, physical or behavior management programs, transition, and other integrated activities.
- To supplement instructional activities or to provide extended practice in instances in which the support assistant has had training from a special education or related services staff, and continues to receive ongoing direction and support from a special education teacher.

From the National Resource Center for Paraprofessionals in Special Education and Related Services (City University of New York) comes this definition of a paraprofessional:

A paraprofessional is an employee:

- Whose position is either instructional in nature or who delivers other direct services to individuals and/or their parents.
- Who works under the supervision of a professional staff member who is responsible for the overall management of the program area including the design, implementation and evaluation of instructional programs and the individual's progress.

Paraprofessionals provide services in the following areas:

- Educational programs
- Physical therapy
- Occupational therapy
- Speech therapy
- Recreation programs
- Early intervention and preschool programs
- Social work/case management
- Parent training/child-find programs
- Vocational training programs and job coaching
- Community programs
- Transition

Paraprofessionals are typically different from professionals in the amount of education, certification required for the job, degree of responsibility, and extent of supervision required.

Because the support of paraprofessionals is so essential to the success of individuals with disabilities, this series is dedicated to improving and enhancing skills for paraprofessionals.

About the Series

Whether you have years of experience working with persons who have disabilities or are just beginning, there are probably many questions you have about the role of a paraprofessional. Some concerns and questions will be very specific to your work setting, while others will be more general. This series, ***Strategies for Paraprofessionals Who Support Individuals with Disabilities,*** will cover both.

This curriculum is primarily for paraprofessionals who are (or will be) working in educational settings (i.e., special and general education). It will, however, also be useful for those in direct service settings, such as vocational programs and residential settings.

The ***Strategies for Paraprofessionals Who Support Individuals with Disabilities*** curriculum has four general, or core, training modules and three specialized modules. The core modules, designed for all paraprofessionals, are:

- Module 1: The Paraprofessional: An Introduction
- Module 2: Providing Cross-Cultural Support Services to Individuals with Disabilities and Their Families
- Module 3: Promoting Self Advocacy and Facilitating Friendships and Socialization Skills for Individuals with Disabilities
- Module 4: Positive Behavior Strategies for Paraprofessionals

The three specialized modules that address competencies needed in specific types of service settings are:

- Module 5: Early Childhood: The Role of the Paraprofessional
- Module 6: Working with Individuals Who Are Medically Fragile or Have Physical Disabilities
- Module 7: Transition: The Role of the Paraprofessional

Each module is designed to stand alone, so you may select any one that best meets your needs. However, it's recommended that everyone begin with Module 1 because it provides a basic framework for work as a paraprofessional and for the material covered in all the other modules.

The training you are about to begin will not only address the current reality for paraprofessionals working with individuals with disabilities, but more importantly, the challenges for the future in your career as a paraprofessional. Paraprofessionals aren't expected to have a total understanding of all the concepts in these modules, but the paraprofessional who has a working knowledge of these core concepts will be most effective.

Guiding Principles

Each module emphasizes six basic guiding principles for paraprofessionals working with individuals with disabilities. Those principals include:

- The individual with a disability is the ultimate locus of control and is the most important member in the decision making process.

- The family is the other primary locus of control. Family involvement is essential in any decision making process.
- The team concept is essential in setting up a plan with an individual. This team includes the individual, the family, and all those working with the individual, including the paraprofessional. The paraprofessional is an essential link between what is and what can be for the individual. The best follow-through on any plan comes from teamwork.
- The community should be the basis for all training, as much as possible. This means that, whether offering real-life examples in the classroom or working in real life situations in the community, the focus must be on the most natural setting and support possible. This is essential so the individual can make connections between what is being learned on a daily basis and the real world. This will help the individual generalize the experience to similar situations in his or her life.
- Inclusion is the goal. This means that individuals with disabilities should be included in the mainstream of society – work, school, and recreation. Devotion to such a model will create the most positive results for the individuals and society as a whole. Inclusion suggests that we can and will all benefit by learning to work and live side by side with each other.
- The most effective paraprofessional will be the individual who has a good self-esteem and is able to be assertive. The assertive paraprofessional is able to ask for support and guidance from staff.

About You: The Adult Learner

We know that the adult learner learns differently than younger learners. This training reflects that understanding. In *Strategies for Paraprofessionals Who Support Individuals with Disabilities* we respect these principles about you, the adult learner:

- You are capable and eager to learn new information.
- You have voluntarily given your consent to become a part of this training, and are spending valuable time and money in order to participate.
- You have a rich range of experiences. Therefore you learn best when new information is built upon your past knowledge and experiences. That's why we will do exercises to help you synthesize the old and new information together.
- You come to a new learning situation as a self-reliant learner who has a good idea of how you want and expect to learn.
- Your willingness to learn is based on a combination of outside forces (family, kids, job, etc.) and inside forces (your anxiety, excitement, fears, etc.). All these factors are going to affect your feelings about learning.

- You come into new learning with your own agenda. You know what you want to get out of the training.
- You have set aside time and reorganized priorities to make this learning part of your already-busy life.
- You expect and genuinely appreciate a facilitator or instructor who is well-informed and well-prepared.
- You need to get actively involved in the learning exercises to get the most out of this curriculum.
- You want to apply what you learn to your own situations. That's when it has real meaning for you.
- You need a safe, comfortable environment in which to learn.
- You want to establish networks with others who are also interested in paraprofessional skills.

Because of these facts about you, trainers will:

- Review and ask questions about what you know.
- Respect and view you as a resource.
- Create a comfortable environment.
- Expect you to take responsibility for your own learning.
- Plan opportunities to practice new skills during class.
- Give examples of how to apply information.
- Use a variety of types of instruction.
- Provide ways to evaluate training.
- Use alternate methods to help you understand.
- Give information in a logical sequence.
- Give time for you to share your experiences.
- Give you the chance to get know other paraprofessionals.

After the Training

You will leave this training with more information about paraprofessionals than you had when you started. It's important to remember that no matter how much knowledge you have about your job, the individuals you work with are your greatest trainers. Each one is unique and has his or her own interests and needs. The greatest responsibility you have is to listen to those interests and needs, remember what you have learned, ask what is needed, and use that information in your working relationship and responsibilities.

Therefore, use this training as a basis and build your skills from this point, drawing upon each setting and individual. Whether client, student, teacher, supervisor, principal, director, or superintendent, you will learn from each. With each setting and situation your confidence, ability, and skills will continue to grow. Remember, this training is only as good as the degree to which you use what you learn; seek assistance so you can "do what you know."

1

Chapter One

Introduction to Self-Advocacy

1 **Introduction**
1 **Section 1 Self-Advocacy**
8 **Summary**
8 **Questions to Ponder**

Introduction

This module is designed to help the paraprofessional facilitate the ability of individuals with disabilities to determine for themselves what they want and need in their lives. It will help you encourage the exercise of self-advocacy skills in the individuals you serve.

Upon completing this chapter, you should be able to:

- Define *self-advocacy, empowerment,* and *interdependence.*
- Recognize your role as a paraprofessional in the self-advocacy process.
- Demonstrate an ability to promote both self-advocacy and empowerment.

Section 1
Self-Advocacy

In recent times, many terms have been used to describe the individual pursuit of independence by persons with disabilities. A list of buzz words around this topic have been developed, none of which are clearly defined. Three terms used to describe this topic are *self-advocacy, empowerment,* and *interdependence.* These terms are defined below:

Self-Advocacy

Self-advocacy is the ability of an individual to know what he or she needs and wants, and then based on those needs and wants, make personal choices. Among the choices is that of asking for support and assistance in order to live and work as independently as possible. It can also be defined as what a person does to communicate (advocate for) his or her own needs or to protect his or her interests or rights. In order to do this, the individual must understand his or her personal strengths and weaknesses. He or she must know what accommodations are needed, based on personal strengths and weaknesses. Self-advocacy is based on one's ability to answer the following four questions:

- What do I want?
- What do I need? (as defined by the individual)
- What do I like?
- What do I dislike?

In *Promoting Self-Advocacy* by Mary Powell and Joan Shoepke (1993), self-advocacy is summarized this way: "Self-advocacy is empowerment. It's not a single act, but rather a process which grows

Activity 1

In addition to reading the descriptions of self-advocacy, empowerment, and interdependence, have students take turns reading aloud sentences in order from the handout entitled "The Dignity of Risk" found in Appendix A. Afterwards, ask students to express their feelings about the statements. Do they feel they are accurate statements about the limitations placed on people with disabilities by society? Do they think those limitations have merit or are fair. Allow the feelings of the group to be expressed, relating the ideas expressed to the importance of the need for individuals to have the right and ability to set their own course.

Show Transparency 1.1

with nurturing. The goals to help the person to fully develop his or her potential for a regular life with regular choices. It can occur in individual or group situations."

Empowerment

Empowerment has been defined in many ways. Two examples include: "Enabling people to obtain the skills, knowledge, and abilities necessary to make their own decisions and gain control of their own lives. Empowerment means leading independent, productive lives" (Robert R. Davilla, former assistant secretary of OSERS). According to the Minnesota Governor's Council on Developmental Disabilities empowerment is defined as "processes whereby individuals achieve increasing control over various aspects of their lives and participate in the community with dignity."

Interdependence

Interdependence is mutual dependence. It means depending on one another. The individual has the ability to know personal strengths and weaknesses, to know what he or she can do independently, and to know how to ask for assistance. It means the individual not only asks of and "takes" from the environment (including the relationships that are part of that environment), but is also asked of and contributes to the environment. It's a level of "determination" one would hope for with all individuals, with or without disabilities.

Depending on the environment you work in, one of the above terms may be used more than another.

The Paraprofessional's Role in Self-Advocacy

No matter what term is used to describe an individual's quest for independence, the paraprofessional and other members of the team have important roles in enabling people to self-advocate. As stated in *Shifting Patterns* (1992): "At a personal level, people can develop the capacities and competencies of empowerment and self-determination only within themselves. *People empower themselves.* Others can assist individuals to gain the skills, knowledge, capacities, and allies they will need to take control of their lives, create and take advantage of opportunities, and overcome barriers."

When parents of individuals with disabilities were asked in a focus group what tips they would give paraprofessionals about encouraging independence in their son or daughter, they advised:

- Watch the individual with the disability. Let him or her take the lead, then help where or when needed.
- Hold yourself back. Don't jump in to do what the person can figure out to do for him- or herself.
- Give extra help when needed.
- Teach the individual to ask for help.

Activity 2

An important aspect of self-advocacy is the family's involvement. As background information and "food" for discussion, have the students read the article "Family Empowerment" from the Beach Center on Families and Disability newsletter found in Appendix B. Encourage discussion about the issues related to family involvement and empowerment. How does this affect the working relationship of the paraprofessional who is often the "go between" between parents and other staff because the paraprofessional is the one who may have the most physical contact with family members on a daily basis? Also discuss the role of the paraprofessional in encouraging the family to let their member make more decisions and choices as the individual moves toward/into adulthood.

- Teach peers how to encourage independence by being role models, and by telling individuals how to act to address their own needs, rather than always jumping in and helping.

You are, or will be, working with people who have unique and sometimes very great needs, and the natural response is often to jump in and help. But self-advocacy is about choices and giving the individual the respect and integrity to always have the opportunity to make personal choices, as everyone deserves.

Consider this poem and think about self-advocacy. What do you think about the poem? How does this relate? How did you feel after you read it?

The Language of Us & Them

We like things.	They fixate on objects.
We try to make friends.	They display attention-seeking behavior.
We take breaks.	They display off-task behavior.
We stand up for ourselves.	They are non-compliant.
We have hobbies.	They self-stim.
We choose our friends wisely.	They display poor peer socialization.
We persevere.	They perseverate.
We love people.	They have dependencies on people.
We go for a walk.	They run away.
We insist.	They tantrum.
We change our minds.	They are disoriented and have short attention spans.
We have talents.	They have splinter skills.
We are human.	They are…?

Adapted with permission from Mayer Shevin, in J. Pearpoint, M. Forest, & J. Snow, *The Inclusion Papers: Strategies to Make Inclusion Work*, 1991.

What Kind of Behavior Are You Promoting?

Listed below are many headings that describe various types or styles of behavior. It's important for you to think about where you "fit in" with these styles. The activity on the following page will help you understand the behaviors you rely on in your work as a paraprofessional.

Activity 3

Have students read the article entitled "Empowerment: Dependence versus Independence" by Frank G. Bowe, Ph.D. from the *OSERS News In Print* newsletter found in Appendix C. Discuss the article with the class in terms of its implications on self-advocacy now with the Americans with Disabilities Act (ADA) legislation.

Activity 4

Ask the students to do this at the beginning of class. Give them about 5–8 minutes to complete circling. Then ask the group to list the behaviors they chose. Write them down. Which behaviors are the most prevalent? Ask the students which behaviors they feel are most supportive of self-determination behaviors. Which behaviors do they feel don't promote self-determination? Make a list of them. Ask the students to, for their own records only, start the behaviors they would like to improve upon in the future that would promote self-advocacy. Ask students in paraprofessional roles to share with those who are not yet in that role.

Activity: Modeling Roles

Think of the phrases that promote self-advocacy below. Think of the phrases that encourage dependency. Think of how you respond to individuals in your work as a paraprofessional. Then circle the twelve phrases which describe how you view your role as a paraprofessional. Which skills do you want to be modeling?

As a Nurturer

- Accepts, allows, encourages
- Seeks out and acknowledges the ideas/expertise each person offers
- Invites
- Requires
- Sees potential in others
- Brings out creativity in others
- Creates a safe environment
- Trusts
- Ignores undesirable qualities in others
- Communicates privately
- Shows others how to sharpen skills
- Self validates
- Validates others
- Defers

As an Innovator

- Experiments; takes risks
- Resists change
- Sees, creates, focuses on possible options
- Is open-ended
- Suggests trying another way or idea
- Assists others in expressing their views
- Accepts differing opinions
- Acts defensively
- Sets up group problem solving and advises
- Brainstorms
- Initiates negotiations
- Recognizes need for more information
- Suggests how or when others might locate alternatives
- Locates alternatives
- Uses resources freely
- Recognizes the need for help

- Caretakes, rescues
- Includes individual in deciding what is needed
- Sees the value of learning from what may seem a mistake or bad experience
- Sees challenges as opportunities to grow
- Deals with "problem" situations

As One Who Cooperates

- Believes in own personal power
- Manipulates
- Empowers others
- Collaborates, cooperates
- Sees that we are all in it together
- Focuses on "being with"
- Shares credit with others
- Values private time and space
- Is always available
- Creates a support network
- Becomes unproductive, overwhelmed, immobilized
- Appreciates and allows silent times
- Feels a need to fill in silences with words; likes to hear self talk

As a Positive Person with High Self-Esteem

- Celebrates self and others
- Apologizes
- Sees people as developing, growing
- Trusts own intuition; encourages others to do the same
- Imagines things as they could be
- Is positive and hopeful about the future
- Acts burned-out, cynical
- Believes that when offered a variety of choices, people will make the best personal choice
- Appreciates humor in self and others
- Takes it all too seriously
- Laughs with self and others
- Perseveres; shows courage

As a Assertive Speaker/Listener

- Speaks easily, tactfully, candidly
- Hides behind jargon
- Uses non-verbal, as well as verbal skills
- Pays attention to requests

- Models gentleness and kindness with self or others
- Models "asking for what I want"
- Initiates or confronts
- Relays back what is seen, heard, felt
- Asks before giving feedback
- Gives feedback, whether or not recipient is agreeable

As an Open-minded Individual

- Treats others as equals
- Accepts persons rather than forming preconceived ideas
- Refuses to put people in slots, categories
- Uses judgments, labels
- When listening, refers issues to the appropriate persons
- Blaming
- Shows courage
- Values differences, disagreements
- Values only sameness, likeness

As a Delegator

- Organizes, prioritizes for self, encourages others to do same
- Models and supports taking responsibility for self
- Takes responsibility for others
- Listens and watches, focusing on strengths, skills that will help person help him- or herself
- Seems controlling
- Encourages independence, risk
- Encourages dependence
- Provides ideas to define, clarify
- Acts as a source of information only when appropriate
- Delegates, with agreement
- Does only for others and feels overloaded

Adapted from *Using Natural Supports in Community Integration* by E. Curtis, New Hats, Inc., P.O. Box 57567, Salt Lake City, Utah, 84157. Telephone 801/268-9811.

Shifting Patterns, Beliefs, and Attitudes

Shifting Patterns is a comparison of the ways individuals with disabilities are often considered versus the ways individuals are considered. Read the "from" and "to" items below and think of these comparisons as you go.

From	To
• No choice	• Choice
• Feeling hopeless	• Feeling hopeful
• Self-doubt	• Belief in self
• Self-blame	• Promoting the possible
• "They owe me"; blaming others	• I am responsible for the future; take control of my own life
• Seeing deficits	• Seeing strengths
• Professionals know better than parents or lay people	• People have different kinds of knowledge
• "We" choose for "them"	• Consumers choose for themselves
• Power over	• Power with and among
• Exclusive ("us and them")	• Inclusive ("all of us")
• Differences as inadequacy	• Differences as assets
• One cultural perspective	• Multicultural perspective
• The system sets the agenda for individuals and families	• Individuals and families setting and pursuing own agendas
• Focus on information to individuals and families so they'll know what experts think is best and act appropriately	• Focus on skills, competencies and knowledge so individuals and families can set and pursue what they think is best
• Focus on changing individuals and families	• Focus on individuals & families changing the system and public policy
• Focus on self-improvement	• Focus on self-determination, self-creation, advocacy and improvement
• Professionals planning for people	• Individuals and families planning for themselves
• A professional team, to which individuals and families may be invited	• A team of family and friends, to which staff who are close to the individual may be invited
• Focus on services into which the individual can fit	• Focus on how the world needs to work so the individual is a member of and contributor to the community

Activity 5

Have two students read the "Shifting Patterns, Beliefs and Attitudes" chart out loud. Have one student read "from" statements and alternate with another student reading "to" statements. After they finish, ask the group their feeling or reaction to the "from" phrases versus the "to" phrases. Discuss any unknown phrases or terms. Do they have an emotional response to one over the other? Do they characterize the individuals they work with or will work with using more statements found in the "from" side more than the "to" side? Ask them to think about going to work in a new setting where the treatment of the individuals with disabilities is characterized more by the "from" column than the "to" column. How would they react to this environment? What steps could/would they make to change the environment? Allow time for good discussion on this topic.

• A preoccupation with test scores, problems, and weaknesses	• A preoccupation with strengths and capacities
• Having one's best interests represented by others, usually families	• Making choices & representing one's own interests
• Being seen and treated as a client	• Representing oneself as a citizen and person with rights
• Life skills training	• Assertiveness/advocacy training

Adapted with permission from the Cornell Empowerment Project and *Shifting Patterns* developed by the Minnesota Governor's Council on Developmental Disabilities, October 1992.

Summary

Understanding and being able to promote self-advocacy and empowerment in an invaluable tool for paraprofessionals working with individuals with disabilities. This chapter defined *self-advocacy, empowerment,* and *interdependence* and discussed your role in the self-advocacy process. It also helped identify behaviors paraprofessionals rely on in their work and offered a comparison of the ways people with disabilities are viewed versus the way "normal" people are considered. These concepts can be applied when assisting individuals with disabilities to become more empowered in all area of their lives. Chapter Two explores ways to put these principles into practice.

Questions to Ponder

- In what ways do you currently promote self-advocacy and empowerment?
- In your job, what are ways you can promote self-advocacy and empowerment?
- What are some ways others encourage and support your empowerment?
- What are three ways individuals with disabilities are often viewed in comparison with individuals without disabilities? Think of ways you can help change this in your role and through your behaviors.

2

Chapter Two

Promoting Self-Advocacy

9 Introduction
9 Section 1 Encouraging Self-Advocacy
15 Section 2 The Art of Negotiation
18 Summary
19 Questions to Ponder

Introduction

How can you as a paraprofessional encourage self-advocacy? What are your attitudes about self-advocacy? How do you respond to it? How do you encourage negotiation? This chapter focuses on ways paraprofessionals can put self-advocacy into practice.

Upon completing this chapter, you should be able to:

- Identify ways you can encourage self-advocacy.
- Recognize your attitude about self-advocacy.
- Define ways people self-advocate.
- Demonstrate an ability to respond to self-advocacy.
- Identify steps you can use to help people learn to negotiate.

Section 1

Encouraging Self-Advocacy

Those who encourage behavior that leads to self-advocacy are true bridge-builders for the future of individuals. Some ways you can encourage self-advocacy are:

- Take time to build trust networks so the individual has confidence in his or her support system and feels the courage to self-advocate.
- Give responsibility to the individual.
- Show appreciation for contributions the individual makes at home, school, and work.
- Ask for the individual's opinion. This gives the individual the understanding that their experiences and ideas have merit and are valued.
- Encourage the individual to participate in problem solving and decision making at all times.
- Accept mistakes.
- Guide the individual through situations until he or she can advocate for him- or herself.
- Get to know the individual and his or her strengths and weaknesses so you can help him or her make connections.
- Start with small goals and work into the big ones.
- Be patient and take time with the individual. Self-advocacy can be scary business.
- Give up control. Let events take their own course and just "happen" when you feel the individual can handle his or her own advocating.

Activity 1

Have students read and discuss this section along with the articles "Advocacy: Noun, Verb, Adjective or Profanity?" in Appendix D, and "Confessions of a Professional" in Appendix E. Ask students to discuss what role the paraprofessional may have as an advocate for an individual or family. Is this informal or formal advocacy? What should it be? Ask the students to share personal experiences as advocates. Discuss the five lessons learned by the professional and how they relate to the students' experiences. Discuss enabling attitudes – when they're appropriate and when they're not. Explain that helping individuals to become self-advocates is tricky business. On the one hand they need you and on the other hand you must "push them out of the nest". Make sure that students realize their role isn't to enable learned helplessness. Discuss this as a group.

Show Transparency 2.1

- Don't fix or change things. Let the individual work things out on his or her own.
- Don't teach the community how to "accommodate". Teach the individual to ask for the specific and appropriate accommodations needed.
- Be responsive.
- Have a commitment to the importance of self-advocacy.
- Be creative with both decisions and judgments.
- Understand that your role in promoting self-advocacy is, at best, unclear. You will be learning with each individual what will be the best techniques to support his or her self-advocacy.

Activity 2

Have the students complete the following scenario outside of the classroom. They should be prepared to discuss the process they applied to reach appropriate self-advocacy with the class upon completion.

"You Create It" Scenario

Pick one choice from each of the items below and then create your own scenario:

The individual is:

- A child under five
- A teenager
- A young adult in college
- An adult in a residential setting

The individual has:

- Never advocated for self before
- Has advocated unsuccessfully
- Is a good self-advocate
- Is aggressive in advocating
- Is passive and doesn't know needs

The individual has:

- A supportive, nurturing family
- A passive, uninvolved family
- A demanding, aggressive family
- No family or family support

The individual is:

- Ready to self-advocate
- Is frightened to self-advocate
- Doesn't know what to do
- Can advocate with support

You have worked with the individual:

- Daily over a long period
- Never
- Only occasionally
- Only in self-advocacy training

The individual:

- Trusts you
- Knows you're patient
- Doesn't like you
- Has had good experiences with you in the past
- Has had bad experiences with you in the past

You are:

- Committed to self-advocacy
- An enabler
- Responsive and perceptive
- Dreading this part of your job

You and the individual are working on advocacy skills in:

- A work situation
- A school situation
- A home situation
- A neighborhood situation
- A relationship situation

"You Create It" Scenario by ______________________
Your Name

Now address the following questions based on your scenario.

- What was the specific situation?

- What I did to promote self-advocacy?

- What did the individual do to be a self-advocate?

- What accommodations needed to be made in the setting to facilitate independence?

- Who asked for those accommodations and how that was received in the setting?

- What part family members, friends, neighbors, teachers, or agency people played in the situation?

- What was the end result of the situation? Was it positive? Negative? How could the process have been better?

Activity 3

Have students complete "Evaluating Your Attitude" following the instructions given. Then have them find a partner and compare their responses. After discussing with a partner, call the group together to discuss what, as a group, they feel are the essential attitudes and beliefs necessary to promote self-advocacy.

Show Transparency 2.2

Activity: Evaluating Your Attitude

In order to promote self-advocacy, you must first evaluate your own beliefs and attitudes. Understanding how you react to individuals with disabilities will help you understand how the community at large reacts. It's also important to be honest with your feelings so that you can approach the issue of self-advocacy. If, for example, your honest belief is that individuals with disabilities have very limited capabilities on the job, and you're working as a job coach, you will probably not promote and encourage the individual's skills. On the other hand, you might behave very differently in that same situation if you felt the "sky's the limit." You would be more likely to help the individual accomplish whatever he or she wanted to accomplish. How you view people limits their ability to advocate and accomplish their goals. You must be honest about this before becoming a promoter of self-advocacy.

With this in mind, complete the following inventory about yourself and your attitudes and beliefs. Read the statements below. Check each statement you truly believe.

- ☐ I believe everyone (regardless of disability) has the right to achieve their goals and dreams.
- ☐ I believe that individuals with disabilities are entitled to reasonable accommodations that will help them achieve their goals.
- ☐ I also believe that there is a point beyond reasonable accommodations for which individuals should not have accommodations made.
- ☐ I believe individuals with disabilities have the ability to know what they want.
- ☐ I believe individuals with disabilities have the ability to make good choices for themselves.
- ☐ I believe individuals with disabilities have the ability to speak out for themselves.
- ☐ I believe individuals with disabilities must ask assertively for what they want and need.
- ☐ I believe it's important to understand your rights, your strengths, and your weaknesses in order to self-advocate.
- ☐ I believe that self-advocates can create a lot of conflict in their advocating, but sometimes that is a necessary part of the process.
- ☐ I believe my major role in advocacy is to guide, encourage, and support individuals toward their desired goals, but the true, effective advocacy must come from the individual him- or herself.

Find a partner and discuss the statements you checked. Compare your "beliefs" with his or hers. Do you differ significantly in your beliefs? Decide together which items you feel are essential to have checked to be a good promoter of self-advocacy.

Questions for Paraprofessionals to Ask Themselves When Promoting Self-Advocacy

The following are "thought" questions for you to read. After reading them, think about how you *really* feel about the questions and how you would answer them. You don't have to write your answers down but may if you wish. Pick two or three questions you want to discuss and form a small group and discuss your reactions or feelings about the questions. This exercise is meant to help you think about your attitudes toward self-advocacy, what you do to encourage self-advocacy, and maybe ways you could improve.

Activity 4

Go through this list and explain and discuss each question. Ask students to examine their behavior in the past and consider how they will or do work with individuals with disabilities. Since we must assume we all have biases to some extent, in what way do their biases show themselves? The above questions may draw out some of those biases. If they do, discuss with students what they can do to readjust their thinking to be more proactive in behalf of individual's self-advocacy.

Activity 5

Discuss with students the importance of them being aware of such "cues" as these ten questions. Sometimes individuals won't act in a very demonstrative way, but still may have good skills to self-advocate and may be asking for help, but the paraprofessional may not recognize it. This can be so disappointing to the individual that it may discourage him or her from advocating in the future. Therefore, the paraprofessional must have a "trained ear" to listen for signs of self-advocating and encourage those signs. Discussing these questions can be one way of creating an awareness for paraprofessional.

Activity 6

Tell the students that these steps are equally appropriate for students or individuals in a work setting. These are steps that are intended to be used with situations as they arise on a daily basis. Detailed plans for self-advocacy will be included in the individualized program to be used on a regular basis.

- Am I listening to the needs, interests, and desires of individuals or am I imposing my own point of view?
- Do I see the human growth and potential of individuals or do I see the "disability" and "limitations"?
- How do I react when an individual is his or her own advocate? Can I handle it?
- Do I have a need to control the individual's decision-making? Could any of my actions be considered a conflict of interest?
- Is it okay for individuals to question my point of view and or give me negative feedback about what I am doing?
- Is it okay for individuals to tell me they don't need me and can make their own decisions?
- Do my actions:
  - Increase the self-respect, self-confidence, and self-reliance of individuals so they feel comfortable taking risks?
  - Decrease dependence on me?
  - Teach individuals a process for making decisions and problem solving?
  - Involve individuals in activities that increase self-understanding and promote being the key player in personal decision making?
  - Encourage individuals to obtain a wide variety of information and points of view so they make informed decisions?
  - Recognize that anger is okay and even justified in many instances and encourage individuals to use that anger toward positive growth and societal change?

If you can answer *yes* to most or all of these questions, you're preparing individuals to become positive self-advocates.

How Do I Know if an Individual is Self-Advocating?

If you can answer *yes* to any of these questions, the individual is appropriately self-advocating. If the individual is doing the following, praise him or her for assertive behavior. If the individual isn't using these behaviors, encourage him or her to do so. Give examples of how this could be accomplished.

Is the individual:

- Asking me for specific help?
- Able to explain his or her disability to me?
- Asking me in a direct manner?
- Communicating slowly and in a manner that I can understand?
- Organized to ask me for specific assistance because he or she planned ahead?
- Clear about his or her specific needs?

- Asking for assistance that seems reasonable given his or her needs and the specific setting?
- Respecting my rights as a paraprofessional?
- Aware of his or her rights?
- Talking about ideas that would help and asking for my input?

Responding to a Self-Advocate

You now know the "cues" of someone who may be appropriately asking for assistance. But what steps do you take when an individual does ask for help? These steps may be useful in helping you develop a plan to support the individual.

- Listen to the individual explain the situation in which he or she is asking for assistance.
- Ask the individual for his or her ideas on possible solutions (accommodations or modifications).
- Talk over the possible solutions with the individual.
- Discuss the positives and negatives of each solution discussed.
- Make sure solutions being discussed relate to the disability area needing accommodation or modification. (Sometimes you may come up with solutions that would be nice but don't really relate to the specific needs of the individual and therefore aren't really considered "reasonable accommodations".)
- Arrive at a solution you can agree on. Be sure to include anyone else in the decision making that will be a part of carrying out the modification or accommodation.
- Set a time-line to implement a solution and follow up with an evaluation of the solution chosen.
- Make adjustments, if necessary, or continue of the solution is working to the satisfaction of the individual.
- Commend the individual for arriving at a solution. Remind him or her that you will continue to "be there" for him or her as needed for future issues and concerns.

Activity 7

Have students try the following situation in small groups, then share their responses with the class.

Situation: A sixth grade student with a learning disability comes to you, the paraprofessional in the special education resource room, and says she has to write a paper on the Civil War for history class. The girl has a severe writing disability and some organizational skills problems. You have been helping her and working with the classroom teacher throughout the year. What solutions will the two of you come up with?

Section 2

The Art of Negotiation

Learning to negotiate is an essential skill that will tie all the other pieces of advocating together for individuals with disabilities. Here are some steps that you can use and adapt with individuals to help them learn how to negotiate for what they want and need in a constructive manner:

- Introduce what you need to the person you need it from. Present your needs clearly.
- Discuss the rationale for your request. When you do this, remember to use your knowledge of your strengths and weaknesses, be specific, be consistent, and most of all, be believable. You will be believable when you state what you know about yourself in a clear, respectful, knowledgeable fashion.
- Discuss example situations where you will need what it is you're asking. In this way you're showing that you aren't "asking for the moon", but that at certain times and in certain situations, you have very specific needs, based on your strengths and weaknesses.
- Express the needs that you have one at a time (step by step) so that the individuals can understand them.
- Explain how this will make a difference to you in your life and in your ability to perform.
- Verbally (or otherwise, if necessary) rehearse your presentation/request. Use someone you trust as an audience. This will help build your comfort level.

Activity 1

Have the students discuss the importance of clearly "training" individuals in negotiation skills as they help them prepare to advocate.

Show Transparency 2.3

To the best of the individual's ability, encourage him or her use the following body language:

- Face the person with whom you're negotiating.
- Use an appropriate voice tone.
- Use appropriate (positive) facial expressions.
- Use good body posture.
- Use good listening skills.

Adapted from *Self-Advocacy* (unpublished) by Steve Hazell and Rud Turnbull, University of Kansas.

Basic Human Rights and Responsibilities

Look at these seven situations in preparation for classroom discussion. Notice the difference between someone's rights and their responsibilities.

Activity 2

Have students read the seven situations from the "Basic Human Rights and Responsibilities" scenarios. Encourage students to notice how important it is to observe individual rights and responsibilities in the negotiation process. Have the students pick a partner and have them discuss their styles of negotiation. Then have students share their observations with the rest of the class.

Situation 1

- **Right:** A person has the right to ask for what he or she wants.
- **Example:** John has the right to ask to borrow his mother's car.
- **Responsibility:** When asking for what he wants, John has the responsibility to state his request specifically and in a calm manner. He also needs to realize that his request may not be granted.
- **Example:** John asks his mother to borrow her car to go to the movies Friday night. His mother, however, has other plans for the car and refuses his request. John has the responsibility to accept his mother's answer, to not throw a temper tantrum, and possibly to discuss with his mother other options for getting to the movies.

Situation 2

- **Right:** A person has the right to try to change things that he or she doesn't like.
- **Example:** James doesn't like his job. He has the right to either try to change the conditions of his current job or find another job.
- **Responsibility:** When trying to make changes, James has the responsibility to state his concerns calmly and directly to the people in charge. Grumbling about a situation but doing nothing to change it is irresponsible behavior.
- **Example:** If James is unhappy with his job and would like to change the situation, he has the responsibility to talk directly to his boss about the matter. He also has the option to quit his job and find another.

Situation 3

- **Right:** A person has the right to make his or her own choices.
- **Example:** Jane has the right to choose what she will do with her life when she finishes high school.
- **Responsibility:** Jane has the responsibility to accept the consequences of her choice and to make sure her choice doesn't take away the rights of others.
- **Example:** After much thought, Jane, an eighteen-year-old high school student, decides she would like to be a construction worker when she finishes school. She knows, however, that her dad would like her to go to college. Jane has the right to choose whether she will go to school or work. She has the responsibility, however, to accept the consequences of this choice. In this case, two possible consequences might be finding a job and dealing with an upset parent. Jane has the further responsibility to make sure her choice doesn't take away the rights of others, including her dad. If Jane tells her

dad about her decision in a calm and direct manner, then she will be acting in a responsible manner. However, if Jane yells at her dad or lies to him, she'll be violating her dad's rights as a parent (among which is the right to be treated with respect).

Situation 4

- **Right:** Mary has the right to say "no."
- **Example:** Mary has the right to say no to a classmate if he asks her to do something that she doesn't want to do.
- **Responsibility:** When saying "no", a person has the responsibility to say it in a calm manner and without preventing other people from exercising their rights.
- **Example:** Mary's friend asks her to skip fifth hour English. Mary doesn't want to so she simply says "no." Mary doesn't need to explain her decision, but may if she chooses. By saying "no" to her friend in a calm yet firm manner, Mary stands up for her right. At the same time, she doesn't prevent her friend from exercising his rights.

Situation 5

- **Right:** A person has the right to privacy.
- **Example:** Anna has the right to have some privacy in the apartment she shares with two roommates.
- **Responsibility:** A person has the responsibility to express her desire for privacy and to make sure that by exercising this right it doesn't infringe upon the rights of others.
- **Example:** Anna shares an apartment with two roommates. She asks a friend, Luis, to come over to watch TV. Anna asks her roommates if she could use the family room for Saturday evening so she could entertain her guest. Marsha, one of her roommates, says it's fine with her because she's going out of town for the weekend. Rosa, the other roommate, says it's okay with her because she's working on an art project in her room.

Situation 6

- **Right:** A person has the right to make mistakes.
- **Example:** Terrell has the right to make the mistake of getting on the wrong bus. This may be unpleasant, but it isn't the end of the world. Making mistakes is one way people learn.
- **Responsibility:** When an individual makes a mistake, he has the responsibility to accept the consequences of that mistake.
- **Example:** If Terrell gets on the wrong bus and is late for work, he has the responsibility to explain what happened to his boss. He also has the responsibility to accept other consequences of his mistake, such as a reduction in pay.

Situation 7

- **Right:** A person has the right to be treated with respect.
- **Example:** Nadine has the right to have her teacher listen to her speak no matter how difficult it might be for Mary to express her ideas.
- **Responsibility:** Every person has the responsibility to treat other people with respect.
- **Example:** If Nadine's teacher is giving an assignment, Nadine has the responsibility to treat her teacher with respect. One way Mary can do this is by listening to what her teacher says rather than talking to her classmates. This shows respect not only for Mary's teacher, but also for her classmates who need to hear the assignment.

All individuals have rights and responsibilities for their behavior. The previous situations have shown in a variety of instances that individuals clearly have rights and with each of those rights comes the responsibility to act out those rights in an appropriate, respectful manner. Along with rights and responsibilities are also choices. Individuals have choices about how they will act out their rights and it's their responsibility to make those choices in an appropriate manner at all times in order not to infringe on the rights of others.

These situations were adapted with permission from *Self-Advocacy* (unpublished) by Steve Hazell and Rud Turnbull from the University of Kansas.

Summary

Understanding self-advocacy and negotiation, and the techniques to promote theses skills, are abilities that paraprofessionals can use to assist individuals with individuals with disabilities to become empowered. As a paraprofessional, being able to identify and reinforce self-advocacy skills facilitates the ability of persons with disabilities to determine what the want and need in their own lives.

This chapter discussed ways of promoting self-advocacy and negotiation for persons with disabilities. Activities provided you with opportunities to evaluate your attitudes concerning self-advocacy and ways you currently promote self-advocacy. Chapter Three explores what it takes to be a successful self-advocate.

Questions to Ponder

- What were your feelings when a person with disabilities self-advocated and you supported his or her efforts? How did you respond?
- What were your feelings when a person with disabilities self-advocated and you *didn't* support his or her efforts? How did you respond?
- In your own job, how have individuals with disabilities self-advocated?
- How do you promote negotiation skills in individuals with disabilities?

3

Chapter Three

What it Takes to Be a Successful Self-Advocate

21 Introduction

21 Section 1 Characteristics of a Skillful Self-Advocate

33 Summary

33 Questions to Ponder

Introduction

In order to support the self-advocacy of individuals with disabilities, you need to know the characteristics of a skillful self-advocate: the necessary behaviors, understanding one's strengths and needs, preparation, and practice.

Upon completing this chapter, you should be able to:

- Define the successful behaviors of a self-advocate.
- Identify passive, aggressive, and assertive behavior.
- Demonstrate effective self-advocacy techniques in difficult situations.
- Assist a person with disabilities to prepare for an individual planning meeting.
- Identify reasonable accommodations.

Section 1

Characteristics of a Skillful Self-Advocate

Many behaviors must be present for an individual to successfully self-advocate, and these skills and behaviors will be introduced in this section, along with activities designed to clarify the importance of these characteristics.

Activity 1

Discuss the attributes of successful self-advocates. Have students add to the list. Discuss what they feel their role as a paraprofessional can and should be toward this success.

Behaviors of Successful Self-Advocates

A self-advocate is one who can:

- Take the initiative to talk with others in person.
- Tell the appropriate person about his or her disability.
- Make his or her needs clearly known.
- Ask to meet needs with an assertive (not aggressive) approach.
- Explain his or her strengths and weaknesses to others to receive appropriate services and who can ask for appropriate accommodations.
- Show self-confidence in describing his or her needs.
- Develop a positive relationship with people.
- Approach the situation calmly and with self-control.
- Supply information about his or her disability to those who will be working with him or her.
- Show respect to those from whom he or she is requesting help,

services and/or support.

- Plan ahead for needs (rather than asking at the last minute).

What other characteristics can you and the class think of?

- ____
- ____
- ____
- ____
- ____
- ____

As a paraprofessional, it's important for you to know what can be expected of the individual. When you understand the individual's abilities, you can help, train, and support the positive attitudes necessary for him or her to be a successful self-advocate. You can expect self-advocacy behaviors to some degree from all individuals. Therefore, it's important to separate things you do for the individual that are necessary, and those things that the individuals should be doing or asking for him- or herself.

You must be careful not to enable individuals to be inappropriately dependent upon you. *Enabling* means to do *for* the individual what he or she could or should learn *to do independently.* Sometimes it's difficult to determine what is enabling behavior and what isn't. The best step to take when you're not sure is to ask your supervisor, or better yet, observe and ask the individual. Notice his or her capacities and work from that point.

Discussing Strengths and Weaknesses

In order for an individual to be able to self-advocate, that person must know his or her personal needs. This means understanding one's strengths, gifts, and capacities and how to build upon these assets. It also means knowing one's weaknesses and limitations and how to accommodate or compensate for those areas. By learning about one's strengths and weaknesses, an individual can develop a strategy, in any given situation, for how to learn or accomplish the task in the best way possible for him or her.

As part of the team process, it's important to share all information including testing findings with the individual. As a paraprofessional working closely with the individual, it's important to share observations about how the individual appears to learn and cope with situations on a daily basis. It's important to encourage staff to share information about the individual (both strengths and weaknesses) with the him or her as a means of helping to develop a better understanding of self. In too many situations, the needs (especially the weaknesses) of individuals are discussed without their involvement. Too often extensive tests are given to individuals to learn their strengths and weaknesses and then never shared with the individual in an understandable way.

It's important to explore with the individual all aspects of his or her life. There are many areas of strengths all individuals have that don't show up on test performance or daily activities but are an important part of a person's life. These may be areas that can be used to compensate or accommodate the individual when observed as a "whole being". The best person to explore these strengths (capacities) and weaknesses (limitations) is the individual him- or herself.

An effective, simple way of exploring these areas with an individual is to collect all the information you can about the individual's strengths and weaknesses from a professional standpoint. Then ask the individual to gather and think about all the information on his or her strengths and weaknesses in all areas of life. Then get together, with the collective information, and make a chart together about including the combined information. Based on the combined information on the chart, you and the individual can work toward finding reasonable accommodations based on individual needs and capacities.

Pages 24 and 25 contain examples of charts you could complete with an individual with this combined information.

Activity 2

Have the students practice using the charts on pages 24 and 25 either with a partner from the class, an individual they are currently working with, a friend or family member, or on themselves. Tell students to be very specific in listing skills. What seems small and insignificant may lead to discovering a vital link to help the individual.

Passive, Aggressive, or Assertive?

Once people understand themselves by making a picture of their strengths, weaknesses, and needed accommodations, they are more prepared to start self-advocating. There are three ways individuals can express their needs: in a passive, aggressive, or assertive manner. It's very important for individuals to know and understand the difference between these three styles and which one will work the best in gaining the support they need. It's crucial for individuals to clearly understand the different ways of expressing needs and the best way to obtain the support they need. The three types of expression are defined as follows:

- **Passive Behavior:** This is when an individual knows he or she needs assistance but is either afraid to ask for help or doesn't really know how to ask. So rather than seeking assistance, he or she just ignores the need or waits passively hoping someone will step in and guess or assume the need.
- **Aggressive Behavior:** This is when an individual knows, or thinks he or she knows what is needed and demands service or asks in a very angry or aggressive way. This method doesn't respect the rights of others and is generally not accepted well by the person from whom help is being sought.

[*Continued on page 26*]

Activity 3

Passive, aggressive, and assertive behaviors were discussed in the first module in this series, *The Paraprofessional: An Introduction.* Referring back to that module may be appropriate here. Explain that it's important for the paraprofessional to have a working understanding of the difference between these three behaviors because they have a daily influence on how the individual learns these behaviors and responds to situations in an assertive, appropriate manner.

Show Transparency 3.1

My Strengths and Capacities

Things I can do and am proud of doing:

In My Neighborhood	In School
In My Place of Worship	In My Social Life
On My Job	In My Clubs & Social Groups

Accommodations that help me be successful:

My Weaknesses and Limitations

Things I have more difficulty with and need support for:

In My Neighborhood

In My Place of Worship

On My Job

In School

In My Social Life

In My Clubs & Social Groups

Accommodations that help me be successful:

- **Assertive Behavior:** This is the behavior we are striving to develop in positive self-advocacy. It's exhibited when an individual knows what support/accommodations he or she needs in a given situation, know who to ask for assistance, and then asks in a clear, concise, polite manner. The assertive person knows his or her legal rights, but isn't rude or aggressive in having those rights meet.

Activity 4

These are suggestions for paraprofessionals to use with individuals who are self-advocating. Everyone is bound to run into the four C's eventually: ***complaints, criticism, conflict, and compliments.*** Individuals need to realize that each of these have potential problems and rewards. Being able to handle conflict and compliments is a skill that is part of independent living. Tell students to discuss these four C's with the people they will work with and help them understand the meaning of each. Help students take an active role and address complaints, criticism, conflict, and compliments with people with whom they work in the natural setting of their daily environment.

Show Transparency 3.2

Self-Advocacy in Difficult Situations

As the paraprofessional working with the individual closely every day, you can help him or her understand they are in charge of their own assertive behavior and sometimes they will encounter especially difficult situations. Techniques for them to use in handling those situations may include:

- When you have complaints, start with the source and state your facts. If you don't get satisfaction, go through the proper channels using available support, until the problem is solved.
- When you're being criticized, listen for the constructive comments about yourself, take them seriously, accept the criticism, but keep it in perspective so that you don't respond in a defensive manner.
- When you're involved in a conflict, state the problem and listen to the other person's perspective. Then brainstorm solutions and select the best choice together. Try the solutions, then evaluate it to see if it was effective. If the solution isn't working, make necessary changes.
- When you're complimented, accept the compliment without expecting more or feeling you must return the compliment.

Be Prepared

Once the individual knows what it takes to be a positive self-advocate, has an understanding of his or her strengths and weaknesses, knows the proper behavior (assertive) to self-advocate, and understands how to be in charge of his or her own behavior, the individual is ready to *get prepared!* This means that the individual has all the tools to advocate, but still needs some skills that you can help provide. The two remaining steps in getting prepared are:

- Sharing the appropriate information about him- or herself with others.
- Asking for accommodations or modifications based on this self knowledge and an understanding of legal rights.

The best way to help the individual use the information learned about him- or herself is to practice preparing for a meeting. Use your experience collecting information on the strengths and weaknesses charts to complete the following scenario as a exercise. You can use this format in the future when helping individuals prepare for meetings. By planning and organizing the individual's thought with him or her in this way ahead of time, he or she will be able to express his or her own needs in the meeting.

Scenario

Let's assume that Jon, an individual you have been working with, is preparing for an transition meeting. He will be graduating from high school and going to work. The following is the information you collected together.

- **Strengths and Capacities:** You and Jon have listed on the strengths and capacities chart that he's had a paper route in the neighborhood for five years and has mowed lawns for neighbors for three years. He has been successful on these jobs and has saved money in a bank account over the years. In school Jon has done well in industrial arts classes, has been on the swim team, and has done well in basic math concepts. He hasn't attended a church. In his social life, Jon has been involved with a group of kids throughout high school that also live in his neighborhood. Jon doesn't have a driver's license, but he takes the bus or rides with friends wherever he goes. In terms of clubs or groups, Jon has been in the swim club for three years. He appears to be well liked by both faculty and students.
- **Weaknesses and Limitations:** Jon has had several academic problems over the years, stemming from his disability. His reading skills are at about the fifth grade level. He has had trouble following complicated directions (both oral and written). Jon has been encouraged to be involved in church youth group activities but feels he has been teased by the group so he doesn't participate. He isn't able to drive and feels this has an impact on his social life. Jon hasn't had a job outside the neighborhood and has never had an indoor job.
- **Planning:** Based on this information, Jon is going to enter the planning meeting and make some decisions about the type of work he wants after high school. You, Jon, his parent(s), a psychologist, teachers, rehabilitation counselor will all be in the meeting. Jon will be asked to state the his experience, what he feels are his strengths and weaknesses, and what support (accommodations/modifications) he will need on the job. Complete the following as a "cheat sheet" for the Jon in preparation for the meeting.

  My key strengths are:

  ____

  ____

  ____

  ____

Activity 5

Have the students fill this out with a partner in class and then discuss it as a group. What are the types of accommodations the students decided upon for this student? What others might be needed on the job? Have students go through this process with the comments on their own strengths and weaknesses charts. Explain to the students how important it is to take time with individuals to prepare them for meetings so they will be able to responsibly advocate for themselves.

My key weaknesses are:

My work experience includes:

The kind of work I am interested in:

The help I will need on the job:

Steps to Self-Directed Individual Planning Meetings

Once an individual is prepared, he or she can function successfully in his or her individual planning meeting and express personal strengths, weaknesses, and desires. Each individual you work with will be at a different level in his or her ability to participate in the meeting. Nevertheless, individuals should be made aware that this is *their* meeting and *their* opportunity to express personal dreams and desires.

Time needs to be spent with the individual prior to the meeting to explain what will happen, what his or her role should be, and how important it will be for him or her to express personal wants and needs in this group. As a part of the planning meeting, you, as the paraprofessional, can assist your supervisor and the individual in preparing the individual for his or her meeting by encouraging him or her to ask for and/or do the following steps in the meeting:

- State the purpose of the meeting.
- Invite everyone in the group to introduce themselves.
- Review past goals to bring everyone up to date.
- Ask for feedback from others in the group.
- State the individual's, family's, and institution/school goals.
- Encourage all to ask questions if they don't understand.
- Be open to different opinions.
- Have the opportunity to state the support he or she will need.
- Summarize the goals.
- Close the meeting by thanking everyone.
- Make a verbal promise to work on the goals until the next meeting.

If the individual has limited communication abilities, plan ways with the team that the individual can interact and participate in the meeting. Work with the individual ahead of time to help prepare him or her to participate as much as possible. Make sure that the individual's needs and wants are not overlooked just because of limited communication or intellectual abilities.

Adapted from *Self-Directed IEP Student Workbook*, Center for Educational Research, University of Colorado at Colorado Springs.

Activity 6

Review and discuss these steps to self-directed individual planning meetings with the class.

Deciding on Reasonable Accommodations

An important part of what it takes to be a successful self-advocate is to know what accommodations the individual will need to be successful in reaching his or her goals. Accommodations don't just refer to job situations. Individuals may need accommodations in social settings, schools settings, residential, neighborhood, or

Activity 7

Explain to participants what an important role they can play in helping individuals decide on a daily basis what to ask for in order to receive the accommodations needed to be successful in all environments. Have them share experiences where they have helped individuals determine their needs and then ask for them appropriately. Explain that one of the pitfalls for paraprofessionals here is knowing when to back out and let the individual take over for him- or herself. There's a very delicate balance that needs to be observed so the individual becomes accustomed to self-advocating as soon as possible. Explain to participants how important they are in helping individuals learn to make decisions about their needs and accommodations in various environments.

work settings. The kind of modifications or accommodations needed will vary depending on the individual. There's no list one can go through and pick the right accommodation to meet the needs of individuals in all settings. "Reasonable accommodations" describes what is needed to accommodate individuals with disabilities because it's language used in the Americans with Disabilities Act (ADA) which was enacted in 1990.

The best way for an individual to receive the accommodations he or she needs is to know what they are. This means knowing strengths and capabilities as well as weaknesses and limitations and also knowing what has worked in the past.

If an individual you're working with is very young or has recently acquired a disability, he or she may not have had enough experience to know what works as an accommodation for him or her in various situations. Some individuals who have had a lifelong disability also don't know themselves very well. Individuals will need you to offer suggestions about what accommodations might work. In order to make suggestions, you should first ask or have someone else find out for you:

- What are your needs in this situation?
- What help do you need from me or others?
- What environmental changes can we create to make this situation work for you?
- What types of needs do you have that we could solve with equipment, technology? (The individual may not know the answer to this but you may have ideas based on how he or she responds and your observation of the situation.)

Based on the answers you receive, develop a plan with the individual to try some accommodations and see what works. If it feels like you're "shooting from the hip," you probably are – but some of the best accommodations were designed this way. Deciding on reasonable accommodations isn't a science. Most of the best accommodations come from these kinds of brainstorming sessions. Successful accommodations are often inexpensive and effective.

Once the individual has had experience with you guiding him or her through the questions above, he or she will begin to feel comfortable determining his or her own accommodations without your guidance. When the individual reaches this point, he or she is ready to advocate in his or her own behalf.

What Are Reasonable Accommodations?

The following are examples of reasonable accommodations in learning situations for individuals with particular learning difficulties. These are typical accommodations requested in school and are just examples to give you an idea of what an accommodation may be in a given situation.

Accommodations for Reading Difficulties

- Have the textbook tape recorded, or do this yourself or have peers do it for him or her.
- Read the textbook to him or her or ask a peer to do it.
- Ask the individual if he or she would rather have directions read aloud, or tests read aloud to him or her.
- Ask the individual if it would help in understanding if he or she had an outline or brief set of directions to follow along to help focus attention.
- Ask him or her if extra time is needed to complete reading tasks.
- Show him or her how to highlight or underline the main points for clarification.
- Suggest that the individual let the teacher or others know if he or she is uncomfortable reading aloud in a group setting.
- Help the individual with reading skills on a individual basis.
- Help the individual to find a peer to help him or her review the important points.
- Teach the individual to work in a quiet area.

Accommodations for Writing Difficulties

- Teach the individual to use a spelling dictionary.
- Teach the individual to learn to use word processing with spelling and grammar checking features.
- Teach the individual to ask someone to proofread his or her work.
- Have the individual dictate written work.
- Suggest that the individual ask if he or she could present information in another way other than written, like a verbal presentation or a drawing.
- Suggest that the individual ask a peer to share his or her notes.
- Tape-record instructions or lectures to listen to later.

Accommodations for Math Difficulties

- Ask the individual to sit near the instruction or direction.
- Suggest that the individual ask for explanation of symbols and steps if he or she isn't sure.
- Teach the individual to write down mathematical processes step-by-step.
- Set up the individual working with a peer who can explain the math necessary to complete the task.
- Show the individual how to use graph paper to keep problems in line.

Show Transparency 3.3

Activity 8

Have students read "Out of My Old Life and Into My New One" by Michael Kennedy, a young man with cerebral palsy, found in Appendix F. This article is meant to illustrate to students the determination of one man and what assertive self-advocacy can accomplish. Discuss Michael's situation and the examples of self-advocacy illustrated in the article. Have the students share situations that may be similar. After students have read the article, have them discuss the following topics with each other. Have any of the students had similar situations with individuals like Michael? Ask students to imagine what Michael's life was like before he attained the level of independence he was capable of. What does this article say to paraprofessionals working with individuals with disabilities? What does it say to all of us about limitations we place on each other?

- Suggest that the individual ask for concrete examples when he or she doesn't understand.
- Suggest that the individual ask for additional time where math is involved.
- Teach the individual how to use a calculator.

Accommodations for Organizational Difficulties

- Teach the individual to ask for an outline of instruction, rules, directions, etc.
- Teach the individual to ask for a schedule of what is going to happen at the beginning of a class, or a job, or a series of instructions.
- Teach the individual to ask for instructions to be repeated if he or she didn't understand them.
- Teach the individual to ask to have instructions written down if needed.
- Teach the individual to ask for individual time with the instructor or supervisor (on a job) for further explanation if he or she doesn't understand what is expected of him or her.

These are just simple examples of accommodations that can be arranged. Always remember that the individual should initiate his or her own accommodations as much as possible. Your role, as a paraprofessional, is to support these efforts toward independence but not to discourage the individual's ability to seek out his or her own opportunity to achieve that independence.

Self-Determination Panel Discussion

You may decide it may be helpful to have a panel discussion in class or with the individuals with whom you work. The following questions may be used to ask the panel: use them to encourage discussion with visiting panel members about their experiences as self-advocates. You may also want to use these questions on the job when you notice that some individuals seem to be better able to express their needs than others. Asking questions, respectfully, can be a very useful learning experience for you in helping other less assertive individuals improve their skills.

- What was the hardest thing for you to learn as you worked to be a better self-advocate?
- Can you give me an example of a time when your efforts at speaking for yourself really paid off?
- Can you give me an example of when speaking up and asking for services or help backfired and got you into trouble?
- What one piece of advice can you give me about advocating, based on your experiences?

Activity 9

An optional activity at this point would be to have a panel discussion. Invite individuals in the area who have disabilities and have developed self-advocacy skills to come into class and discuss their experiences, both positive and negative, in this endeavor. Ask each panel member to prepare to give initial statements about their lives, their histories, and how they have become self-advocates. After these initial statements, have the students use the following questions to enhance discussion with the panel members. At the end of the discussion, thank the panel member and students for participating in the discussion. If you can gather a good panel together one time, ask their permission to videotape the discussion. This videotape can then be used at a later time with other students or for further discussion.

- What can I do as a paraprofessional on my job to facilitate self-advocacy among individuals with whom I work?
- Can you remember one person in your life who helped encourage you to self-advocate? Who was that? What did he or she do to help you?

Adapted from *Self-Determination: The Journey to Independence* developed by Michael Wehmeyer and Hank Bersani, Jr.

Summary

This chapter discussed characteristics of a skillful self-advocate. Specific behaviors were identified, including assertiveness, self-confidence, planning, stating needs clearly, and respect for others. A capacity chart was used to identify and build on self-advocacy skills. Passive and aggressive behaviors were also discussed – particularly why they aren't successful behaviors.

Questions to Ponder

- What are five behaviors of a successful self-advocate?
- Have you personally observed a skillful self-advocate? What made you feel he or she was skillful?
- Have you ever had an experience where you felt you were a skillful advocate for yourself but were not successful?
- How can you encourage individuals to advocate for themselves?

4

Chapter Four

Rights of People with Disabilities

35 Introduction
35 Section 1 Individual Rights
49 Section 2 Disability-Related Laws
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56 Questions to Ponder

Introduction

In order to be an effective self-advocate, you not only need to demonstrate skillful behaviors, but also possess knowledge of the appropriate rights and laws. By having knowledge of such rights and being able to apply it in specific situations, you hold another key to empowerment.

Upon completing this chapter, you should be able to:

- Identify the rights of the self-advocate, the consumer rights statement, and the Resident Bill of Rights.
- Discuss the Americans with Disabilities Act, Section 504 of the Rehabilitation act of 1973, IDEA, and Part H of IDEA.
- Discuss the use of behavioral interventions.

Section 1

Individual Rights

People with disabilities have the same rights as any other human beings. In order for an individual to be able to self-advocate, he or she must understand his or her rights and it's your role as a paraprofessional to assist people in the understanding of these rights. The following are three examples of rights statements as published in the manual *Promoting Self-Advocacy* by Mary Powell and Joan Shoepke: the *Self-Advocacy Workbook List, Consumer Rights Statement,* and the *United Nations Universal Declaration of Human Rights.* When using these as examples, think about other rights that apply specifically to the individuals with whom you work.

Rights Statement 1: *Self-Advocacy Workbook List*

- The right to life.
- The right of choice.
- The right to freedom.
- The right to try to be happy.
- The right to make up your own mind.
- The right to choose the people you want to be with.
- The right to be listened to.
- The right to eat what you want.
- The right to go to bed when you want.

Adapted with permission from *We Can Speak for Ourselves*

Activity 1

Have the students read these three sets of rights. Explain that these are examples of basic human rights for which all people are entitled. Explain to the students that these are included in the module because sometimes people with disabilities are denied the basic rights of others on the basis of their disability. Explain that it's important to remember as a starting point that these are basic human rights for all. Have a discussion about these rights, especially the United Nations Universal Declaration of Human Rights and how those rights may be and have been denied individuals with disabilities.

Rights Statement 2: *Consumer Rights Statement*

Rights are the things that the law says you should get, like the training that you need to live and work like everyone else. You have many rights when you work here:

- You have the right to be by yourself when you want to be.
- You have the right to be treated well by staff.
- You have the right to a safe place to work where you won't get hurt.
- People do not have the right to say or do bad things to you or to keep you from eating or to take your money.
- You have the right to know the rules about working here.
- You need to know what to do when you don't like something.
- You have the right to speak up for yourself.
- You have the right to ask for an advocate, or someone to speak up for you.
- You can ask that a report about how you're doing be given to you, your family, or your advocate.
- You have the right to have your questions or concerns answered as soon as possible.
- You have the right to have a place to keep your things.
- You have the right to use a telephone for private calls.
- None of your rights can be taken away without a chance for you to tell your side of the story.
- You have a right to get the training you need to live and work more independently.
- You have the right to see a doctor when you need to and without waiting a long time.
- Staff cannot do things that might physically hurt you.

Adapted from *Read My Lips*

Rights Statement 3: *The United Nations Universal Declaration of Human Rights*

Whereas Member States have pledged themselves to achieve, in cooperation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore, the General Assembly proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

1 All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act toward one another in a spirit of community.

2 *A:* Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
B: Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self governing or under any other limitation of sovereignty.

3 Everyone has the right to life, liberty and security of person.

4 No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

5 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

6 Everyone has the right to recognition everywhere as a person before the law.

7 All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

8 Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

9 No one shall be subjected to arbitrary arrest, detention or exile.

10 Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of one's rights and obligations and of any criminal charge against him.

11 *A:* Everyone charged with a penal offense has the right to be presumed innocent until proved guilty according to law in a public trial at which one has had all the guarantees necessary for one's defense.
B: No one shall be held guilty of any penal offense on account of any act or omission which did not constitute a penal offense, under national or international law, at the time when it was committed. Nor shall a heavier penalty be im-

posed than the one that was applicable at the time the penal offense was committed.

12 No one shall be subjected to arbitrary interference with one's privacy, family, home or correspondence, nor to attacks upon one's honor and reputation. Everyone has the right to the protection of the law against such interference or attacks.

13 *A:* Everyone has the right to freedom of movement and residence within the borders of each State.
B: Everyone has the right to leave any country, including one's own, and to return to his country.

14 *A:* Everyone has the right to seek and to enjoy in other countries asylum from persecution.
B: This right may not be invoked in the case of persecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

15 *A:* Everyone has the right to a nationality.
B: No one shall be arbitrarily deprived of his nationality nor denied the right to change one's nationality.

16 *A:* Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
B: Marriage shall be entered into only with the free and full consent of the intending spouses.
C: The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

17 *A:* Everyone has the right to own property alone as well as in association with others.
B: No one shall be arbitrarily deprived of property.

18 Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief; and freedom, either alone or in community with others and in public or in private, to manifest one's religion or belief in teaching, practice, worship and observance.

19 Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontier.

20 Everyone has the right to the freedom of peaceful assembly and association. No one may be compelled to belong to an association.

21 *A:* Everyone has the right to take part in the government of one's country, directly or through freely chosen representatives. Everyone has the right of equal access to public service in one's country.
B: The will of the people shall be the basis of the authority of

government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

22 Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international cooperation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for one's dignity and the free development of one's personality.

23 *A:* Everyone has the right to work, to free choice of employment, to just and favorable conditions of work and to protection against unemployment.
B: Everyone, without any discrimination, has the right to equal pay for equal work.
C: Everyone who works has the right to just and favorable remuneration ensuring for oneself and one's family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
D: Everyone has the right to form and to join trade unions for the protection of one's interests.

24 Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

25 *A:* Everyone has the right to a standard of living adequate for the health and well being of oneself and of one's family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond one's control.
B: Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

26 *A:* Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.
B: Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance, and friendship among all nations, racial, or religious groups, and shall further the activities of the United Nations for the maintenance of peace.
C: Parents have a prior right to choose the kind of education that shall be given to their children.

27 *A:* Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
B: Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary, or artistic production of which one is the author.

28 Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

29 *A:* Everyone has duties to the community in which alone the free and full development of one's personality is possible.
B: In the exercise of one's rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order, and the general welfare in a democratic society.
C: These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

30 Nothing in the Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

This section on rights was adapted with permission from *Promoting Self-Advocacy, Instructor's Guide* by M. Powell and J. Shoepke, presented by the Minnesota Association of Rehabilitation Facilities (MARF), the Minnesota Developmental Achievement Center Association (MnDACA), and Brainerd/Staples Regional Technical College (B/SRTC) as part of a collaborative grant from the Bush Foundation, 1993.

Activity 2

Have students read and then discuss the various components of the "Residents' Bill of Rights". Tell students this is an example of the type of rights statements they should find or be given upon request in any residential setting. Use this as another example to illustrate the rights that are mandated and provided for individuals with disabilities.

The Residents' Bill of Rights

The following Bill of Rights is another example of the rights mandated by law and provided especially for individuals with disabilities. You may see a version of these rights in many forms in different residential environments.

A: Purpose of the Residents' Bill of Rights

The purpose of the Residents' Bill of Rights is to identify the rights of residents in Minnesota's community residential facilities which are licensed as health care facilities and certified as intermediate care facilities for persons with mental retardation (ICF/MR). Services to persons with developmental disabilities should be based on individual interests and needs and be designed to preserve human dignity, and to protect both civil and human rights.

Home and Community Based Waiver programs use the Home Care Bill of Rights which may be obtained from the Minnesota Department of Human Services, 612/296-3971.

B: Introduction to the Bill of Rights

The following is the introduction which is included in the Residents' Bill of Rights:

This document describes the rights of residents in Minnesota's community residential facilities which are licensed as health care facilities and certified as Intermediate Care Facilities for person with Mental Retardation (ICF/MR). These rights are set forth in M.S. 144.651-2, and in Volume 42, Code of Federal Regulations, Sections 442.403 and 442.404.

Definitions: "Resident" means a person who is admitted to a non-acute care program including extended care facilities, nursing homes, and board and care homes for care required because of prolonged mental or physical illness or disability, recovery from injury or disease, or advancing age.

Public policy declaration: It is declared to be the public policy of this state that the interests of each resident be protected by a declaration of a Residents' Bill of Rights which shall include but not be limited to the following:

It is the intent of the legislature and the purpose of the Residents' Bill of Rights to promote the interests and well-being of residents of community facilities. No community program may require a resident to waive these rights as a condition of admission to the program. Any guardian or conservator of a resident or, in the absence of a guardian or conservator, an interested person, may seek enforcement of these rights on behalf of a resident. An interested person may also seek enforcement of these rights on behalf of a resident who has a guardian or conservator through administrative agencies or in probate court or county court having jurisdiction over guardianships and conservatorships. Pending the outcome of an enforcement proceeding, the community program may, in good faith, comply with the instructions of a guardian or conservator. It is the intent of this section that every resident's civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the program shall encourage and assist in the fullest possible exercise of these rights.

The resident is to be fully informed, as evidenced by written acknowledgment witnessed by a third party, prior to or at the time of admission and during the stay of these rights and of all rules and regulations governing resident conduct and responsibilities. A copy of the law is to be given to the resident. The interests of the resident and, where appropriate, guardians, next of kin, sponsoring agencies, representative payees or the public shall be protected by, but not limited to, the following policies and procedures:

C: Individual Rights

Listed below are each of the rights contained in the Residents' Bill of Rights.

The Right to Information About Rights

Residents shall be told at admission that there are legal rights for their protection during their stay at the program or throughout their course of treatment and maintenance in the community and that these are described in a written statement of the applicable rights and responsibilities set forth in this section. In the case of persons admitted to residential programs as defined in MN Statutes 253C.01, the document shall also describe the right of a person sixteen years old or older to request release as provided in section 253B.04, subdivision 2, and shall list the names and telephone numbers of individuals and organizations that provide advocacy and legal services for persons in residential programs. Upon receipt of this statement and a full explanation, the resident must acknowledge the receipt in writing. Residents already in the program must be provided with written amended statements if these provisions are changed. Reasonable accommodations shall be made for those with communicative disabilities and those who speak a language other than English. Current program policies, inspection findings of state and local health authorities, and further explanation of the written statement of rights shall be available to residents, their guardians or their chosen representatives upon reasonable request to the administrator or other designated staff person, consistent with Chapter 13, the data practices act, and section 626.557, relating to vulnerable adults.

The Right to Courteous Treatment

Residents have the right to be treated with courtesy and respect for their individuality by employees of or persons providing service in a community residential program.

The Right to Appropriate Medical and Personal Care

Residents have the right to appropriate medical and personal care based on individual needs. Appropriate care for residents means care designed to enable residents to achieve their highest level of physical and mental functioning. This right is limited where the service is not reimbursable by public or private resources.

Isolation and Restraints

A minor who has been admitted to a residential program as defined in MN Statutes 253C.01 has the right to be free from physical restraint and isolation except in emergency situations involving a likelihood that the resident will physically harm self or others. These procedures may not be used for disciplinary purposes, to enforce program rules, or for the convenience of staff. Isolation or restraint may be used only upon prior authorization of a physician, psychiatrist, or licensed consulting psychologist, only when less restrictive measures are ineffective or not feasible and only for the shortest time necessary.

The Right to Know Who is Providing Physicians Services

Residents shall have or be given, in writing, the name, business address, telephone number, and specialty, if any, of the physician responsible for coordination of their care. In cases where it is medically inadvisable, as documented by the attending physician in a resident's care record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative.

The Right to Know Who is Providing Services

Residents who receive service from an outside provider are entitled, upon request, to be told the identity of the provider. Residents shall be informed, in writing, of any services which are provided to those residents by individuals, corporations, or organizations other than their program. Information shall include the name of the outside provider, the address, and a description of the service which may be rendered. In cases where it is medically inadvisable, as documented by the attending physician in a resident's care record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative.

The Right to Information about Treatment

Residents shall be given by their physicians' complete and current information concerning their diagnosis, treatment, alternatives, risks, and prognosis as required by the physician's legal duty to disclose. This information shall be in terms and language the resident can reasonably be expected to understand. Residents may be accompanied by a family member or other chosen representative. This information shall include the likely medical or major psychological results of the treatment and its alternatives. In cases where it is medically inadvisable, as documented by the attending physician in a resident's medical record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative. Individuals have the right to refuse this information. Every resident suffering from any form of breast cancer shall be fully informed, prior to or at the time of admission and during her stay, of all alternative effective methods of treatment of which the treating physician is knowledgeable, including surgical, radiological, or chemotherapeutic or combination of treatments and the risks associated with each of these methods.

The Right to Participate in Planning One's Own Treatment

Residents shall have the right to participate in the planning of their health care. This right includes the opportunity to discuss treatment and alternatives with individual caregivers, the opportunity to request and participate in formal care conferences, and the right to include a family member or other chosen representative. In the event that the resident cannot be present, a family member or other representative chosen by the resident may be included in such conference.

If a patient or resident who enters a program is unconscious or is unable to communicate, the program shall make reasonable efforts as required under paragraph *C* to notify either a family member or a person designated in writing by the patient as the person to contact in an emergency that the patient or resident has been admitted to the program. The program shall allow the family member to participate in treatment planning, unless the program knows or has reason to believe the patient or resident has an effective advance directive to the contrary or knows the patient or resident has specified in writing that they do not want a family member included in treatment planning. After notifying a family member but prior to allowing a family member to participate in treatment planning, the program must make reasonable efforts, consistent with reasonable medical practice, to determine if the patient or resident has executed an advance directive relative to the patient or resident's health care decisions.

For purposes of this paragraph, "reasonable efforts" include 1) examining the personal effects of the patient or resident; 2) examining the medical records of the patient or resident in the possession of the program; 3) inquiring of any emergency contact or family member contacted under this section whether the patient or resident has executed an advance directive and whether the patient or resident has a physician to whom he or she normally goes for care; and 4) inquiring of the physician to whom the patient or resident normally goes for care, if known, whether the he or she has executed an advance directive. If a program notifies a family member or designated emergency contact or allows a family member to participate in treatment planning in accordance with this paragraph, the program is not liable to the patient or resident for damages on the grounds that the notification of the family member or emergency contact or the participation of the family member was improper or violated the patient's privacy rights.

In making reasonable efforts to notify a family member or designated emergency contact, the program shall attempt to identify family members or a designated emergency contact by examining the personal effects of the patient or resident and the medical records of the patient or resident in the possession of the program. If the program is unable to notify a family member or designated emergency contact within twenty-four hours after the admission, the program shall notify the county social service agency or local law enforcement agency that the patient or resident has been admitted and the program has been unable to notify a family member or designated emergency contact. The county social service agency and local law enforcement agency shall assist the program in identifying and notifying a family member or designated emergency contact. A county social service agency of local law enforcement agency that assists a program in implementing this subdivision is not liable to the patient or resident for damages on the grounds that the notification of the family member or emergency contact or the participation of the family member was improper or violated the patient's privacy rights.

Treatment Plan

A minor who has been admitted to a residential program as defined in MN Statutes 253C.01 has the right to a written treatment plan that describes in behavioral terms the case problems, the precise goals of the plan, and the procedures that will be utilized to minimize the length of time that the minor requires treatment. The plan shall also state goals for release to a less restrictive program and follow-up treatment measures and services, if appropriate. To the degree possible, the minor resident and his or her parents or guardians shall be involved in the development of the treatment and discharge plan.

The Right to Continuity of Care

Residents shall have the right to be cared for with reasonable regularity and continuity of staff assignments as far as program policy allows.

The Right to Refuse Care

Competent residents shall have the right to refuse treatment based on the information required above. Residents who refuse treatment, medication or dietary restrictions shall be informed of the likely medical or major psychological results of the refusal, with documentation in the individual record. In cases where a resident is incapable of understanding the circumstances but has not been adjudicated incompetent, or when legal requirements limit the right to refuse treatment, the conditions and circumstances shall be fully documented by the attending physician in the resident's medical record.

The Right to Refuse to Participate in Experimental Research

Written, informed consent must be obtained prior to a resident's participation in experimental research. Residents have the right to refuse participation. Both consent and refusal shall be documented in the individual care record.

The Right to Be Free from Abuse

Residents shall be free from mental and physical abuse as defined in the Vulnerable Adults Protection Act (Section 626.557, Subd. 2d). "Abuse" means any act which constitutes assault, sexual exploitation, or criminal sexual conduct as referenced in the Vulnerable Adults Act or the intentional and non-therapeutic infliction of physical pain or injury, or any persistent course of conduct intended to produce mental or emotional distress. Every resident shall also be free from non-therapeutic chemical and physical restraints, except in two possible situations: 1) as authorized in writing after examination by a resident's physician for a specified and limited period of time and only when necessary to protect the resident from self injury or injury to others; or 2) in fully documented emergencies if necessary to protect the resident from himself or others, if the use is authorized by a professional staff member identified in written policies and procedures as having the authority to do so, and the use is reported promptly to the resident's physician by the staff member.

The Right to Treatment Privacy

Residents shall have the right to respectfulness and privacy as it relates to their medical and personal care program. Case discussion, consultation, examination, and treatment are confidential and shall be conducted discreetly. Privacy shall be respected during toileting, bathing, and other activities of personal hygiene, except as needed for resident safety or assistance.

The Right to Confidentiality of Records

Residents shall be assured confidential treatment of their personal and medical records, and may approve or refuse their release to any individual outside the program. Residents shall be notified when personal records are requested by any individual outside the program and may select someone to accompany them when the records or information are the subject of a personal interview. Copies of records and written information from the records shall be made available in accordance with this subdivision and the Minnesota statutes governing access to health records (144.335). This right does not apply to complaint investigations and inspections by the Department of Health, where required by third party contracts, or where otherwise provided by law.

The Right to Know about Services Available

Residents shall be informed, prior to or at the time of admission and during their stay, of services which are included in the program's basic *per diem* or daily room rate and that other services are available at additional charge. Facilities shall make every effort to assist residents in obtaining information regarding whether the Medicare or Medical Assistance program will pay for any or all of the aforementioned services.

The Right to Responsive Service

Residents shall have the right to a prompt and reasonable response to their questions and requests.

The Right to Personal Privacy

Residents shall have the right to every consideration of their privacy, individuality, and cultural identity as related to their social, religious, and psychological well-being. Program staff shall respect the privacy of a resident's room by knocking on the door and seeking consent before entering, except in an emergency or where clearly inadvisable.

The Right to Have Grievances Heard

Residents shall be encouraged and assisted, throughout their stay in a program or their course of treatment, to understand and exercise their rights as residents and citizens. Residents may voice grievance and recommend changes in policies and services to program staff and others of their choice, free from restraint, interference, coercion, discrimination, or reprisal, including threat of discharge. Notice of the grievance procedure of the program or organization, as well as address and telephone numbers for the Office of Health Program Complaints and the area nursing home ombudsman pursuant to the Older Americans Act, section 307(a)(12) shall be posted in a conspicuous place. Every residential program as defined in MN Statues 253C.01, and ever program employing more than two people that provides outpatient mental health services shall have a written internal grievance procedure that, at a minimum, sets forth the process to be followed; specifies time limits, including time limits for program response, provides for the resident to have the assistance of an advocate; requires a written response to written grievances; and provides for a timely decision by an impartial decision maker if the grievance is not otherwise resolved. Compliance by residential programs as defined in MN Statutes 253C.01 with section 144.691 is deemed to be compliance with the requirements for a written internal grievance procedure.

Protection and Advocacy Services

Residents shall have the right of reasonable access at reasonable times to any available rights, protectionists services and advocacy services so that the resident may receive assistance in understanding, exercising, and protecting the rights described in this section and other law. This right shall include the opportunity for private communication between resident and a representative of the rights protection service or advocacy service.

The Right to Communicate Privately

Residents may associate and communicate privately with persons of their choice and enter and, except as provided by the Minnesota Commitment Act, leave the program as they choose. Residents shall have access, at their expense, to writing instruments, stationery, and postage. Personal mail shall be sent without interference and received unopened unless medically or programmatically contraindicated and documented by the physician in the medical record. There shall be access to a telephone where residents can make and receive calls as well as speak privately. Facilities which are unable to provide a private area shall make reasonable arrangement to accommodate the privacy of resident's call. This right is limited where medically inadvisable, as documented by the attending physician in a resident's care record, where programmatically limited by a program abuse prevention plan pursuant to Section 626.557, subd. 14, clause 2, this right shall also be limited accordingly.

The Right to Have and Use Personal Property

Residents may retain and use their personal clothing and possessions as space permits, unless to do so would infringe upon rights of other residents, and unless medically or programmatically contraindicated for documented medical, safety or programmatic reasons. The program must either maintain a central locked depository or provide individual locked storage areas in which residents may store their valuables for safekeeping. The program may, but is not required to, provide compensation for or replacement of lost or stolen items.

The Right Not to Perform Services for the Program:

Residents shall not perform labor or services for the program unless those activities are included for therapeutic purposes and appropriately goal-oriented in their individual medical record.

The Right to Manage Financial Affairs

Competent residents may manage their personal financial affairs, or shall be given at least a quarterly accounting of financial transactions on their behalf if they delegate this responsibility in accordance with the laws of Minnesota to the program for any period of time.

The Right to Associate

Residents may meet with visitors and participate in activities of commercial, religious, political (as defined by the Minnesota statues regarding voting while residing in a community residential program, 203B. 1) and community groups without interference at their discretion if the activities do not infringe on the right to privacy of other residents or are not programmatically contraindicated and documented in the resident's record. This includes the right to join with other individuals within and outside the program to work for improvements in long term care.

The Right to an Advisory Council

Residents and their families shall have the right to organize, maintain, and participate in resident advisory and family councils. Each program shall provide assistance and space for meetings. Council meetings shall be afforded privacy, with staff or visitors attending only upon the council's invitation. A staff person shall be designated the responsibility of providing this assistance and responding to written requests which result from council meetings. Resident and family councils shall be encouraged to make recommendations regarding program policies.

The Rights of Married Residents

Residents, if married, shall be assured privacy for visits by their spouses, and if both spouses are residents of the program, they shall be permitted to share a room, unless medically contra-indicated and documented by their physicians in the medical records.

The Rights of Transfers and Discharges

Residents shall not be arbitrarily transferred or discharged. Residents must be notified, in writing, of the proposed discharge or transfer and its justification no later than thirty days before a discharge from the program and seven days before transfer to another room within the program. This notice shall include the resident's right to contest the proposed action, with the address and telephone number of the area nursing home ombudsman pursuant to the Older Americans Act (Section 307(aX12). The resident, informed of this right, may choose to relocate before the notice period ends. The notice period may be shortened in situations outside the program's control, such as determination by utilization review, the accommodation of newly admitted residents, a change in the resident's medical or treatment program, the resident's own or another resident's welfare, or nonpayment for stay unless prohibited by the public program or programs paying for the resident's care, as documented in the medical record. Facilities shall make a reasonable effort to accommodate new residents without disrupting room assignments.

The Right to Know the Rules

Every resident shall be fully informed, prior to or at the time of admission and during the stay at a program, of the rights and responsibilities set forth in this section of all rules governing resident conduct and responsibilities.

Section 2

Disability-Related Laws

Show Transparency 4.1

Individuals with disabilities and their families are protected under several laws. It's important for individuals with disabilities to understand this and know what laws may apply to them and the rights they have in a particular situation, whether it be work, school, or home. Therefore, examples of laws have been added to this section on rights so you, as a paraprofessional, have a basic understanding of what some of the laws are affecting the rights of individuals with disabilities.

The following are examples of laws that affect individuals with disabilities. This isn't an all-inclusive list, however these are the laws most often referred to in schools and in residential and work settings.

Show Transparency 4.2

The Americans with Disabilities Act

The most recent law affecting individuals with disabilities is the Americans with Disabilities Act of 1990 (ADA). Read the Fact Sheet from the U.S. Department of Justice and then the article "The Kindness of Others" found in Appendix H to give you a better background of the law and its implications.

Activity 1

Have students read the Fact Sheet on ADA, found in Appendix G, and discuss the main points of the law. Have students discuss the impact the law has had on Roberta L. Juarez based on her article "The Kindness of Others" in Appendix H.

Section 504 of the Rehabilitation Act of 1973

The Rights of Individuals with Disabilities Under Federal Law: As part of the Rehabilitation Act of 1973 (Public Law 93-112) Congress enacted Section 504, the first federal civil rights law protecting the rights of individuals with disabilities. Section 504 provides that, "no otherwise qualified handicapped individual in the United States... shall, solely by reason of... handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

This law applies to state and local agencies and governments if they receive any federal money.

This law protects any person with a disability who is "otherwise qualified", just like ADA. That means the person with the disability must be able to perform the necessary tasks (with accommodations and modifications if needed) in spite of the disability. This means, if the disability doesn't prevent the individual from doing an adequate performance on the job, he or she is entitled to the job and cannot, under federal law, be denied the job. For example, a person who is mildly retarded who can pass the drivers license test is entitled to be hired to drive the school van because he or she has proven the ability to perform the necessary tasks in spite of the disability.

Section 504 also applied to school. If a student is in need of accommodations or modifications to learn, he or she is entitled to reasonable accommodations. For example, a person who uses a wheelchair may enroll in a community college and find that the department he or she needs to access doesn't have a ramp or elevator. The school must accommodate that student to access the information. They may do that by relocating the class or lab, or by putting in an elevator or curb cuts. Under Section 504, students who may have learning disabilities are entitled to readers, notetakers, books on tape, or other accommodations to facilitate their learning.

Activity 2

Read and discuss the Section 504 Fact Sheet found in Appendix I and other information with students. Remind students how important it is for the individuals with whom they work to understand their rights under Section 504 and other laws.

Section 504 came long before ADA but has been recently updated and still covers some situations that ADA may not.

For further information about Section 504 of the Rehabilitation Act, refer to the Fact Sheet provided in the appendices.

Individuals with Disabilities Education Act (IDEA)

IDEA is a federal law (PL 101-476) which was formerly called the Education for All Handicapped Children Act (PL 94-142). There are certain minimum standards all states must comply with under IDEA and then each state can add to that compliance with additional statutes. Minnesota Chapter 3525 and Minnesota Laws on Special Education along with IDEA spell out the rights of parents for their children in special education. Some of these rights include the right to:

- Agree or disagree to the school's request to test the child.
- Have the child given a test that isn't discriminatory based on race or disability once agreement to assessment is given.
- Receive a written copy of the assessment results
- Have assessment results explained thoroughly.
- Have an independent evaluation if parents disagree with the school's assessment. In this case, the school must pay for the evaluation unless, through a due process hearing, the evaluation given by the school is determined to be appropriate.
- Have parents as equal members of the student's planning team that decides if the student needs special education and if so, to what extent.
- Have someone accompany parents to the Individualized Education Plan (IEP) conference.
- Agree or disagree with the action suggested by the school.

Activity 3

Discuss the rights of parents under IDEA. Ask for student input. Relate the knowledge of these laws and their importance to the ability of individuals and their parents to advocate.

Public Law 99-457 (Part H of IDEA)

This federal law requires schools to serve young children with disabilities beginning at birth. The Individual Family Service Plan (IFSP) is the written document, like the IEP, for this law. In this plan, the needs of children are planned from birth to the age of three. Minnesota has developed an IFSP plan. As of the fall of 1993, all services described in the IFSP (by all the agencies involved) must be implemented.

Material on IDEA adapted with permission from PACER Center, Inc., 4826 Chicago Ave. S., Minneapolis, MN 55417, (612) 827-2966

Activity 4

Because so many paraprofessionals in schools deal with behavioral challenges, this section should lend itself to discussion. Encourage students to discuss the pros and cons of this ruling and to relate personal experiences. Remind students that the discipline decisions for students they work with should be directed from their supervisor.

Minnesota Rule 3525.2925: Use of Behavioral Intervention with Pupils

As another example of Minnesota laws that provide rights to individuals with disabilities, the Behavioral Intervention Procedures for Students with Disabilities is included in this section. This law is specifically directed to rules governing the discipline procedures used with students in school who have disabilities.

In 1989, the Minnesota State Board of Education was directed by the Legislature to adopt rules governing the use of aversive and deprivation procedures for students with disabilities. The Board was asked to draft rules which promote the use of positive behavioral interventions, and to ensure that aversive or deprivation procedures, when appropriate for a student, are included in that student's Individual Education Plan (IEP). The rule, which went into effect in January 1992, is intended to encourage the use of positive approaches to modify students' behavior.

Three categories of behavioral interventions are listed in Minnesota's Proposed Permanent Rule for Use of Behavioral Interventions with Pupils Who Have Disabilities. They are *exempted procedures, prohibited procedures,* and *regulated procedures.*

Each school district is to revise district policies, where necessary, and to provide any necessary staff development to appropriately implement the new rule. Each district should distribute their written discipline policy during IEP meetings, and review common practices in terms of appropriateness for a particular student.

Exempted Procedures

Exempted procedures are planned instructional techniques which are common practices in schools, and consistent with the school discipline policy. Exempted procedures may include, but are not limited to:

- The use of corrective feedback;
- The use of physical assistance to facilitate the completion of a response (such as guiding a child's hand to teach a handwriting skill where there is no resistance);
- Requesting that a student leave an activity for a brief period of time, or the temporary delay or withdrawal of goods, services, or activities as a consequence of their inappropriate use.

Exempted procedures would appear on an IEP when they are used as instructional techniques to help a child meet IEP goals and objectives.

Prohibited Procedures

Prohibited procedures are those procedures which, under Minnesota law, have been declared illegal for use in schools with children who have disabilities. Such procedures are never to be used by teachers or other school staff. Since they are expressly prohibited, they would never appear on a student's IEP.

The following procedures are prohibited in Minnesota for use with students who have disabilities:

- Corporal punishment;
- Requiring students to stand or sit in a position causing physical pain, the use of intense sounds, lights or other sensory stimuli as an aversive stimulus;
- The use of noxious smell, taste, substance or spray as an aversive stimulus;
- Denying or restricting a student's access to equipment such as hearing aids and communication boards;
- Faradic skin shock;
- Totally or partially restricting either of a pupil's auditory or visual senses; *or*
- Withholding regularly scheduled meals or water.

Regulated Procedures

Regulated procedures are any interventions used in a planned manner that meet the definition of an aversive or deprivation procedure (see *Definitions* on the last page of this section). Regulated procedures may be permitted as instructional strategies only when positive or less intrusive methods of encouraging behavior change have been tried without success. Any regulated procedure that is being considered must be clearly articulated in a Behavioral Intervention Plan (BIP), as part of a student's IEP, and can be implemented only with the signed consent of the parents or in an emergency situation. Regulated procedures include:

- The use of manual restraints
- The use of mechanical or locked restraints (e.g., handcuffs)
- The planned use of suspension or dismissal from school
- The use of time-out (where the student is removed from the educational program and may be placed in an isolation room or similar space), *or*
- The temporary delay of regularly scheduled meals or water not to exceed thirty minutes (except in an emergency).

If a regulated procedure is being considered for use with a student who receives special education services, a professional with expertise in the use of positive approaches to behavior management must be a member of the IEP team.

Assessment

An assessment must be performed before any regulated behavioral interventions are recommended or initiated. The assessment must examine the purpose of the intervention, the effect of the behavior exhibited by the student, and its seriousness. The assessment summary must describe:

- The behavior for which a regulated procedure is recommended;
- A base-line measurement of the behavior;
- Documentation of two positive behavioral interventions, and any extra interventions attempted and their effectiveness;
- A review of frequent use of *Exempted Procedures* (e.g., sitting in the hallway or being sent to the principal's office);
- Documentation that other treatable causes for the behavior have been ruled out (health, medical, etc.);
- What alternative procedures have been considered and ruled out and why, *and*
- A description of the proposed regulated procedure.

Positive Behavioral Interventions

Before any regulated behavioral intervention can become a part of the IEP, the school must: 1) document that it has tried and was unsuccessful with positive approaches to manage the offending behavior, and 2) show that the purpose of the intervention is to enable the student to develop appropriate skills. (The use of Regulated Procedures should not be considered just to eliminate unwanted behaviors, or for the convenience of staff).

If the two positive behavioral interventions have not been successful in meeting the IEP goal a team meeting must be convened to review the student's IEP. If the IEP team decides that the use of a regulated procedure is necessary to meet the goal, the procedure must be written into a Behavioral Intervention Plan in the IEP. The BIP must list:

- The target behavior and a base-line measurement of its frequency and severity;
- A description of the proposed behavioral intervention procedure;
- The conditions under which the procedure will be used;
- An explanation of why the procedure was chosen;
- A statement of the expected behavior change that will occur;
- A description of any discomfort, risk, or side effects;
- The conditions or circumstances under which the intervention can or must be discontinued prior to team review;
- The anticipated effects if the procedure isn't used;
- Who will implement the program;
- The team review and evaluation date, not to exceed two months;
- Coordination with home or care facility, *and*
- The parent's informed consent (which may be withdrawn at any time by notifying the program administrator; the procedure must be stopped immediately upon parental request).

Parental Consent

Parents must be contacted within three days of their having withdrawn consent to the Behavioral Intervention Plan in the IEP, to determine the need to review and amend the Behavioral Intervention Plan and the need to convene an IEP meeting for a change in placement or program. If parents are divorced but have joint legal custody, informed consent must be obtained from both parents before using a regulated procedure.

Emergencies

In the case of emergencies, regulated procedures may be used to protect a student or other person from injury, emotional abuse, or to prevent severe property damage, even if those procedures are not written into the IEP however, emergency procedures that are used twice or more per month require that a team meeting be called to see if the IEP continues to meet the needs of the child.

Any time a regulated procedure is used in an emergency (any time that the use of the procedure hasn't been planned in the IEP), district administration and parents must be notified immediately.

Time-out

One of the most frequently used regulated procedures is time-out. Exclusion time-out occurs when a child is removed from his or her regularly scheduled educational program. Seclusion time-out is when a child is placed in a specially designed isolation room. The use of time-out must be addressed in a Behavioral Intervention Plan as part of a child's IEP. Included in the BIP must be a provision for continuous monitoring of the child during time-out, the criteria for the child's return to his regular activities, access to water and restrooms if time-out exceeds fifteen minutes, and documentation of the number of occurrences of time-out and the length of time for each time-out. Time-out rooms must be safe for children, with walls and floors covered to guard against injury. Light switches must be outside the room. A time-out room must have an observation window for continuous monitoring, have smoke and fire monitoring devices, be well lit, clean, heated, and ventilated, and must measure at least five by five feet.

Independent Review Committee

An Independent Review Committee must be available in each district as an option for either parents or school staff, to review the Behavioral Intervention Plan (BIP). The team must contain at least two members who aren't employees of the district. Parents may appoint one member of the team if they desire. Districts must inform parents of their right to request a review; the responsibility of the committee is to review relevant assessment and make recommendations regarding the Behavioral Intervention Plan. The decision of the Independent Review Committee is advisory only and has no power to override the decision of the IEP team; it should be viewed as a "second opinion" when either the parent or the school has concerns regarding the planned interventions for a particular child. The committee must include persons who are knowledgeable about cultural and ethnic issues as well as about behavioral interventions.

Definitions

- **Aversive stimulus:** an object used or an event or situation occurring immediately after a specified behavior in order to stop the behavior (a consequence perceived as unpleasant).
- **Aversive procedure:** the planned application of an aversive stimulus (the planned use of consequences).
- **Deprivation procedure:** the planned delay or withdrawal of goods, services, or activities the child would otherwise receive if an identified behavior occurs or in an emergency situation.
- **Time-out:** a procedure in which a student is completely removed from the educational activity. Seclusion time-out occurs when a student is placed in a specially designed isolation room or similar space.
- **Emergency:** a situation in which immediate intervention is necessary to protect a student or others from physical injury, or to prevent severe property damage.

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Summary

Knowing your rights and how to use them in specific situations is a key point in the self-advocacy process. It's also beneficial to know where to get new or additional information about rights and laws. This chapter discussed specific rights and laws specific to individuals with disabilities.

Questions to Ponder

- What are three of your individual rights? How did you learn about these rights? How do you learn about the rights of individuals with disabilities?
- How do you feel when your rights are being violated?
- As a paraprofessional, what do you do to assure the rights of an individual with whom you're working aren't being violated?

5

Chapter Five

Making a Commitment to Self-Advocacy

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61 Summary
61 Questions to Ponder

Introduction

In this section you will read about ideas you can use to promote self-advocacy with individuals you work with. Think of what you do or will do on a daily basis as a paraprofessional. Compare what you do with the sections below: how do you compare? What can you do to improve your promotion of self-advocacy?

Upon completing this chapter, you should be able to:

- Describe ways you and others can encourage and promote self-advocacy for individuals with disabilities.
- Describe ways the community can encourage self-advocacy for individuals with disabilities.

Section 1

Promoting Self-Advocacy in Individuals with Whom You Work

Read the following tips: they can be used as ways for you to promote and encourage independence, empowerment, and self-advocacy in your setting.

Tips for Encouraging Self-Advocacy

- Make a commitment to yourself, that promoting self-advocacy is crucial to the future success of the individual.
- Create a positive environment in whatever setting you're with the individual.
- Involve the administration in your efforts to encourage self-advocacy.
- Promote self-advocacy as a philosophy that will encourage independence.
- Involve individuals with disabilities as a group to work toward their own advocacy.
- Prove to other "non-believers" that providing opportunities for people to advocate for themselves is the best guarantee for their success. Share stories highlighting self-advocacy at work.
- Ensure that goals for the development of empowerment and self-advocacy are part of the team process and the individual planning process.

Activity 1

Participants can use these tips as ways to promote and encourage independence, empowerment and self-advocacy in their setting. Tell students that an atmosphere must be created where it's the norm to expect individuals to self-advocate. They can be a big part of that atmosphere by carefully nurturing individuals toward their capacity and their own level of independence and then sharing those successes with other staff members and administration. Have students discuss ways they can promote independence.

Activity 2

Discuss these points with the class as a lead-in to the activity called "Promoting Self-Advocacy".

What Works to Help People Advocate for Themselves?

People (parents, relatives, friends, and staff people) need to see and treat the individual as a responsible person. Some ways to promote that are:

- Firmly believe the individual has the right to choices, both in everyday life and setting life goals.
- Don't label the person, but get to know him or her as an individual.
- Ask and listen with care to what the person wants, what the person's goals are, and what specific help the individual needs. Do not assume you know what he or she needs.
- Focus on the individual's capabilities rather than his or her inabilities.
- Match support to the individual instead of fitting the person to what support is available.
- Encourage the individual to work on what he or she wants to work on, even if it's hard to see how far the person can go toward the goal.
- Work with the individual to find ways to make what the individual wants possible by helping to problem solve and to connect the individual with people who can help and be trusted.
- Realize that some of the most valuable learning comes from mistakes. The individual has as much right to make mistakes as anyone else.
- Avoid using labels. When labels are used, expectations are diminished. People do not expect someone with "that label" to be able to speak for themselves to make their own choices, or to be heard.
- Encourage individuals to participate in integrated neighborhood activities. Individuals with disabilities need to be seen as active members in the community who have a valuable contribution to make. When this happens, the old segregation stereotypes can be eliminated.

"What Works to Help People Advocate for Themselves?" is adapted from *Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves*, Report #90-4, October 1990, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

Promoting Self-Advocacy

What does this mean for you as a paraprofessional working with individuals with disabilities? How can you promote self-advocacy with the individuals with whom you work and still support them in ways they need? How are you supposed to know when you're giving too much support and when you aren't giving enough? Make a list of ways you can promote self-advocacy of individuals with whom you work. Bring it to class to discuss with the group.

- In the classroom, I can promote self-advocacy by:

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- In the community, I can promote self-advocacy by:

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- On the job with individuals, I can promote self-advocacy by:

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- In the neighborhood, I can promote self-advocacy by:

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- Within the family, I can promote self-advocacy by:

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- Within myself, I can promote self-advocacy by:

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Activity 3

Have students complete this as a homework assignment. If they aren't in a work setting yet, have them either brainstorm ideas they could use to promote self-advocacy or interview someone in their community that would have good ideas, such as a rehab counselor, teacher, or a school counselor. Students should bring this form back to the next session filled out and then form small groups to discuss their ideas. Have each group share their ideas with the class. Make a master list of these ideas and give each student a copy for future reference.

Activity 4

Tell students that in their position as a paraprofessional, they can be very influential in encouraging individuals and their families to get involved in the change process and make their communities better for individuals with disabilities. Tell them these are some of the ways they can encourage action, but what are some others? Encourage discussion around these action steps.

Activity 5

Have the students read the article "Who Can Teach Change Better?" found in Appendix J. Have the students read this article as another perspective of how and advocate can relate to individuals as an advisor, as well as an advocate. Ask them how they view themselves as paraprofessionals. Can they see their role as also one of advising individuals toward their own independence? Have students discuss this with a partner. What should their role be in advising?

Show Transparency 5.1

Activity 6

Have students read the NICHCY newsletter on self-determination found in Appendix K.

What Can Be Done To Strengthen the Commitment to Self-Advocacy?

Read the following action steps you can take with individuals and their families to improve their lives and their ability to promote self-advocacy. What other steps would you suggest for your community? Write them down in the space provided.

Encourage individuals with disabilities (and their families) to:

- Speak for themselves by becoming politically active
- Involve community leaders in their lives and their issues
- Influence the way the media presents people with disabilities
- Participate in disability service boards, councils, task forces, etc.
- Reach out into the community for help

Teach individuals with disabilities (and their families) how to:

- Become informed about government action and laws related to disabilities.
- Work on committees for local, regional, and national reform
- Bring community leaders into the issues of individuals and their families.
- Watch the way people with disabilities are shown in advertising, on television, and in movies. If it isn't accurate, write and call companies to educate and make them aware.
- Read how individuals with disabilities are reported, described in the newspaper, magazines, etc. If it isn't accurate, write and call to educate and make others aware.
- Find out what committees and task forces are doing in behalf of individuals with disabilities in the community.
- Think about their relationship with service providers. Are they addressing the issues. Are they serving the needs? If not, work to change this.
- Find out what others are doing nationally to create change and promote advocacy.
- *Other steps:*

Adapted from *Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves, Report #90-4*, October 1990, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

Summary

As a paraprofessional, you can make a commitment to promote the self-advocacy of individuals with whom you work. This chapter discussed specific tips like creating a positive environment, promoting the self-advocacy philosophy, ensuring empowerment goals, and sharing stories. Also discussed were ideas of how others and the community could promote and make a commitment to self-advocacy for individuals with disabilities. Some tips included not labelling people, listening, making no assumptions about people, and participating in inclusion activities.

Questions to Ponder

- What personal commitment will you make to promote self-advocacy in the individuals with whom you work?
- Have you seen families promote self-advocacy for a family member who has a disability?
- How have you seen communities promote self-advocacy for people with disabilities?
- What do you feel is the most important thing you could teach individuals and their families about self-advocacy?

6

Chapter Six

Facilitating Friendships & Socialization Skills

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Introduction

Individuals with disabilities who have traditionally been served in segregated settings are now becoming full members of society – in the classroom, in the workplace, in the neighborhood. But physical integration doesn't automatically lead to social integration. The physical presence of persons with disabilities in all settings isn't, in itself, enough. Even though formal integration has often taken place, individuals with disabilities are still quite isolated in the environment.

Individuals with disabilities need the skills to acclimate to the environment, make friends, and develop long-lasting relationships. That's why it's important for someone in the individual's life to have the skills to facilitate the development of friendships. This module is designed to give background and practical suggestions to paraprofessionals to assist individuals in these efforts.

Upon completing this chapter, you should be able to:

- Identify the philosophy in facilitating friendships for individuals with disabilities.
- Describe the three kinds of activities that help people build connections with others: finding opportunities, interpretation, and accommodations.

Section 1

Facilitating Friendships and Socialization

It may seem artificial to say we need to facilitate friendships, that friendship should be something that just happens. But relationships between any two people don't just happen. They take work. And teaching individuals with disabilities how that "work" happens is very important.

Positive relationships and friendships are important to everyone. It enhances learning, creates a sense of belonging, fosters necessary interdependence, and (especially for individuals with disabilities) helps create a feeling of, "I'm like everyone else. I'm not different. I'm accepted."

No one person can be the sole source for facilitating friendships. All the people who work with the individual need to know his or her needs and desires to establish and help explore opportunities and strategies for facilitating friendships. Ultimately, the best facilitator is the individual him- or herself. Helping the individual attain the skills to facilitate personal friendships successfully

Activity 1

This section serves as an introduction to students. It can be read independently and then discussed as a group. When discussing this, ask students what they think happens when one group is segregated from society. Ask them to share any experiences they might have had in facilitating friendships with individuals with disabilities.

is the ultimate goal.

Friendships can't be forced on people. Because you as a paraprofessional often work individually or in small groups with people, you can facilitate relationships and foster them between individuals in their natural daily environment.

Activity 2

Ask students to fill out this twelve point "Friendship Quotient" individually. If they have comments or feelings about any of the statements, ask them to write those under each statement. Then go through the questions, item by item with the entire group and ask for comments anyone has for each statement. Hopefully they will have strong feelings about integrated vs. segregated environments for socialization skill development. Encourage them to discuss their personal biases about friendship development between persons with disabilities and persons without disabilities. Tell the students in this module they will learn skills to facilitate persons in relationships so they can learn to develop healthy friendships in school work and in community settings.

Show Transparency 6.1

Check Your Friendship Quotient

Mark whether you think the following statements are truth or myth. There are no wrong answers. Write any reaction you have next to the statements. This will facilitate group discussion.

☐ ☐ ☐ 1 The enabling of people with disabilities is important to help them make friends and self-advocate.

☐ ☐ ☐ 2 Government funding trends indicate that creating jobs is of greater importance than creating relationships.

☐ ☐ ☐ 3 Paraprofessionals are in key positions to facilitate friendships between individuals in natural settings (work, school, recreational activities).

☐ ☐ ☐ 4 With all the responsibilities and needs of individuals, it's hard to find time to observe ways to facilitate friendships.

☐ ☐ ☐ 5 Most assessments focus on a person's academic deficits rather than on personal aspirations and requests.

☐ ☐ ☐ 6 The "service" system keeps individuals with disabilities on the receiving end of relationships where they're not expected to contribute and therefore have little opportunity to learn how to establish personal relationships.

☐ ☐ ☐ 7 Most individuals with disabilities don't have many real opportunities to establish friendships.

☐ ☐ ☐ 8 Part of the reason people with disabilities don't often find and establish long-lasting relationships is because of the attitudes of society about persons with disabilities.

☐ ☐ ☐ 9 If people with disabilities are not well integrated into society, their chance for establishing friendships with persons without disabilities is slim.

☐ ☐ ☐ 10 When encouraging independence and facilitating friendships, the focus should be on diminishing and fading support.

☐ ☐ ☐ 11 People with disabilities never totally blend in because subtle social rules and cues are impossible to teach.

☐ ☐ ☐ 12 Self-advocates are happier working, living, and socializing with people like themselves.

Adapted from *Using Natural Supports in Community Integration* (1990) by E. Curtis, M. Dezelsky, and C. Coffey, Salt Lake City, Utah: New Hats, Inc.

Activities and Building Connections

Show Transparency 6.2

According to Zana Lutfiyya (1988), friendship facilitation is defined as "providing opportunities where people can comfortably come together to meet each other." Facilitation means that someone (in this case, maybe the paraprofessional) is taking the lead or the key responsibility to ensure that individuals are making the necessary connections with peers that may develop into friendships. Facilitation is an unobtrusive process which taps the expertise of those who know the individual and are willing to help the process along. When needed, the facilitator should talk through the problems in relationship building and be there to help foster and nurture the friendship development. And, just like in self-advocacy, the facilitator also needs to know to back out and allow the individual to foster and nurture the friendship on his or her own.

Lutfiyya identifies three kinds of activities that help people build connections with others: *finding opportunities, interpretation,* and *accommodation.*

- **Finding Opportunities:** This means actually setting up activities, events, or situations that can bring people together. In order to do this, one has to know the individuals involved, their interests, and try to create or find situations and activities around similar interests.
- **Interpretation:** This means helping the individual with the disability present him- or herself in a positive way to others. The individual needs to learn how to present him- or herself based on strengths, common interests, assets, and positive human qualities. In this way, individuals with and without disabilities can look to each other for friendship based on their common attributes (and not be turned away by each others' differences).
- **Accommodation:** This means making necessary changes in the environment so the individual with a disability can interact with others in the best possible way. It means helping to facilitate an environment that feels comfortable for all to interact with each other without feeling awkward.

Adapted from *Reflections on Relationships Between People with Disabilities and Typical People* by Z.M. Lutfiyya, Syracuse University, The Center on Human Policy, Syracuse, NY, 1988.

Activity 3

Have the students break up into small groups and brainstorm what they would do in the following situations to facilitate friendships by: finding opportunities, interpretation, and accommodations. Have them meet for ten minutes in these groups and write down their answers. Then have the groups share and discuss their results with each other.

Group Exercise: Facilitating Friendships

The following three situations are examples in which paraprofessionals can facilitate friendships. Read each situation and then break into small groups to discuss these. As a group, determine the opportunities, interpretations, and accommodations. Be prepared to share your group's answers with the entire class.

Situation 1

Carol is a paraprofessional in a classroom for students with significant behavior support needs in an elementary school (grades 1–5). She and the supervising teacher have been working all year with Fred, who's ten years old. Fred usually ends up in their "time out" area whenever he's required to work in small groups on writing assignments in the regular classroom. He acts out against other children. There's one friend in the class, José, who usually brings Fred down to time out, but other than that they have little to do with each other. Carol learns that Fred and José live in the same neighborhood, ride the same bus, and go to the same church, but have never really gotten to know each other. They rarely interact unless the teacher asks José to bring Fred to time out. When asking Fred about José, he speaks of him as a close friend. Carol feels there is potential here to develop this relationship. What steps can Carol take with Fred and José using the three steps: finding opportunity, interpretation, and accommodation?

- Finding opportunities:

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- Interpretation:

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  ____

  ____

- Accommodations:

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  ____

  ____

Situation 2

Lisa works at a family-style restaurant. She's been there for nine months. Her job coach and the restaurant trainer are very pleased with her work. She is polite to customers. Many of the customers know Lisa because they all live in the neighborhood. When they start a conversation with Lisa she's nice, but doesn't make real "contact" with them. She says she likes her job. When Bob, the job coach, asked her if she was making friends on the job, she looked at him and said, "I didn't know I was supposed to." There are other young women Lisa's age that work at the restaurant with her. Bob learned they've tried to be friendly to Lisa and ask her to do activities with them, but they say she is so "shy" she always says no. What can Bob do to facilitate friendships on the job for Lisa?

- Finding opportunities:

- Interpretation:

- Accommodations:

Situation 3

Andy lives in a group home in an established neighborhood in a large city. He rides the bus daily to his job at a nearby printing shop where he separates garbage and recyclable materials and other odd jobs. He sees the same people at work each day, the same people on the bus, the same people when he's out in the neighborhood, and the same residents and staff people in his group home. Andy expressed to Alice, a group home paraprofessional, that he felt lonely. He related all the people in his life he comes in contact with every day (as stated above) but he says he has no real friends and he feels sad. What can Alice do to facilitate friendships for Andy?

- Finding opportunities:

- Interpretation:

- Accommodations:

Summary

This chapter gave background information and practical suggestions for paraprofessionals to assist individuals with disabilities acclimate to the environment, make friends, and develop long-lasting relationships. By filling out the "Friendship Quotient" checklist, you were able to gain a better understanding of your feelings as they relate to facilitating friendships.

Questions to Ponder

- How do you make friends and develop long-lasting relationships?
- How can you support the individuals with whom you work to attain the skills to make friends and develop long-lasting relationships?

Chapter Seven

7

Issues in Developing Friendships for Individuals with Disabilities

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77 Section 7 Issues in Having a Partner
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Introduction

There are many issues relating to the development of friendships for individuals with disabilities. This chapter discusses a number of them, including understanding the importance of community ties; developing friendships, acquaintances, and membership in the community; keeping in touch; being a part of a family; having a partner; and being a good neighbor.

Upon completing this chapter, you should be able to:

- Understand the importance of community ties and friendships.
- Understand issues surrounding developing and sustaining acquaintances, friendships, interests, and membership in the community.
- Understand issues surrounding being part of a family, having a partner, or being a good neighbor.

Section 1

The Importance of Community Ties and Friendships

Show Transparency 7.1

The importance of community and the sense of belonging for all people can't be underestimated. Many people with disabilities often have missed the typical opportunities throughout their lives to meet and develop friendships naturally. They have lived a life more dependent upon others than people without disabilities. This makes it more difficult to establish natural friendships and ties. It's so important for persons working and living with individuals with disabilities to realize the need for connections and ties and help facilitate that in any way possible. It's the connection that we feel with others that gives our lives meaning. Some of those connections may be strong, others may be weak. Some of those connections come from work, school, church, the neighborhood, and some come from close friends and family. Each type of connection or tie has importance and meaning. Critical elements that determine the strength of connections or ties to someone may be:

- **Time:** The amount of time spent with someone helps to determine the strength of the relationship. If you're a paraprofessional working one to one with a person who has medical needs, you may spend eight hours closely working with him or her daily. Without realizing it, you may be the most important person in the individual's life by virtue of the time you spend together. This means you can have a tremendous impact on modeling relationship behavior with him or her.

- **Intensity:** The amount of emotion attached to the relationship with an individual equals the intensity of that relationship. If there's a great deal of emotion in a relationship, there will be more intensity in those ties than in other relationships where there's less emotional attachment. If a paraprofessional has worked with the same supervisor for many years, has gone through many family issues together and many challenging students or individuals and many work related changes together, the ties to that supervisor are probably very strong because much emotion is attached to the relationship. If a new paraprofessional comes on staff with this team, his or her ties (in the beginning) will be weak, with little emotion involved.
- **Intimacy:** The amount of trust and confidence that is shared with individuals determines the level of intimacy. Two co-workers who have shared many work and family experiences together over the years and have shared their fears, hopes and dreams, have developed a level of intimacy with each other. Co-workers who happen to ride the same bus or each lunch in the cafeteria at the same time, but interact seldom, have a much weaker tie and don't share a level of intimacy.
- **Reciprocity:** Part of creating strong ties is in the exchange people have with each other. That exchange may be services between each other such as sharing equipment, or giving help to someone on the job, or it may be sharing living space. All relationships (either weak ties or strong ties) require some give and take. The level of give and take involved partly determines the strength of the tie between people. If neighbors share buying and using lawn equipment they have closer ties than people who simply greet each other when entering an elevator. Both are example of reciprocity, at different levels.

There are many important connection sources for all people. These are also essential for individuals with disabilities as a means for developing relationships. Some sources include friendships, acquaintances, memberships in clubs and organizations, keeping in touch with others, being part of a family, having a partner, being a neighbor and knowing neighbors. Although each of these areas has the potential for developing relationships, for individuals with disabilities, there can also be particular challenges. Knowing and understanding these challenges can help prepare you, as a paraprofessional, to better facilitate friendships. The following sections will look at each of these "sources of ties" in terms of what the difficulties may be for individuals with disabilities. Each section will then address some ways that staff can help alleviate these difficulties.

Section 2

Issues in Developing Friendships

Activity 1

Discuss with the class other ways to facilitate friendships. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Living at home with parents or in large group homes, many people with disabilities find themselves with very limited opportunities to make friends. They may find themselves tied pretty closely to their parents' social lives, surrounded mainly by people of an older generation, or by company only of their parents' choice. Or they may find that "services" put limits around with whom and where they meet people. For instance, the size of the building or the way it looks may make it harder for people to mix naturally. When large numbers are grouped together, it's easy for segregated group arrangements to prevail.

Attempts to provide volunteers or befrienders can be very helpful, particularly when they mean that one helpful citizen is matched up with one person with a disability. The one-to-one matching often doesn't happen and volunteers work with whole groups. In such cases, it isn't clear what roles the volunteers play or how they differ from staff.

Show Transparency 7.2

Some services are so arranged that almost every part of life happens under one roof or on one site – living arrangements, daytime activities, leisure and recreation. This means that most people with disabilities meet relatively few people who are not either other people with disabilities or staff who are paid to be with them. Even these staff members move in and out of people's lives. When these well known staff people leave, there's no one left who knows the individuals with disabilities well enough to be able to sustain past friendships. Because of limited opportunities for making friends, many people with disabilities find themselves with few friendships in the first place. Meeting people and making friends leads to the second important process – sustaining friendship – doing all those things which help keep friendships alive. Strong relationships can survive many challenges, but if the friendships must be sustained through long separation, distance, and lack of communication, it probably won't survive.

Friendship – What Helps Keep It Alive?

Of all the different ways of being connected with others, friendship is probably the most important. The essence of friendship is that it's freely given and that makes it particularly difficult to "arrange". These ideas could help you facilitate for those you serve:

- Evaluate the individual's present circle of relationships by exploring these questions with him or her:

  - What have the individual's life experiences been?
  - Who are the people in the individual's life?
  - What kind of roles does the individual play in those relationships?
  - Where does the individual spend time?
  - In what activities does the individual participate?
  - What works and what doesn't work for this individual?
  - What are the individual's interests, gifts, abilities?
  - What does the individual have to contribute to others?
  - What help does the individual need?
- Pay particular attention to recognizing friendships, especially when the individual him- or herself may not be able to tell you much about it directly.
- Don't disrupt friendships by doing things such as transferring people a long way away, or moving them from school to school (or house to house), or shifting staff who are just getting acquainted with individuals.
- When someone does have to move and an important relationship is under threat, take extra care to find ways of maintaining that relationship and seeing that other opportunities are created.
- Ensure that people with disabilities have lots of positive encouragement and active support for developing connections with people thereby increasing the chances that acquaintances may grow into friendship.
- Other suggestions that work:

Section 3

Issues in Developing Acquaintances

Many acquaintances grow out of everyday life experiences and are a fairly natural part of the business of living in a family, a neighborhood, and going to school or work. When people with disabilities have these activities in their lives, they are more likely to develop acquaintances in natural settings. Too often people with disabilities don't have these opportunities. What they often have instead is a series of organized activities that are structured by families, teachers, or service providers. Individuals make acquaintances, but often their closest acquaintances are with you, as parapro-

Activity 1

Discuss with the class other ways to facilitate acquaintances. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

fessionals or other service providers. The natural act of developing acquaintances is not natural or easily available.

Acquaintances seem to be sustained by simple acts like getting together for a cup of coffee, going to a movie together, or saying "hi" while walking along the street. Simple acts of hospitality – buying a round of drinks, making a cup of tea – are all the stuff of acquaintanceship. With time, some people unused to these skills are able to learn them. Others will always need someone on hand to ensure these customs and common social skills are observed, and that the person with a disability gets to participate, even if he or she may not be skilled in initiating them or carrying them through on their own.

The lack of a rich circle of acquaintances and sensitive help which could develop and sustain it means that many people with disabilities simply lack company a lot of the time. They may spend a lot of time with other people but have no sense of connection to them. Perhaps even more important, individuals with disabilities may lack some of the vital kinds of useful contacts which acquaintances bring into the lives of everyone.

Acquaintances – What Helps Create Them?

Since forming and sustaining an acquaintance doesn't demand too much of the people involved, it's relatively easy to foster. Some ways of helping are:

- Use places where other people are, and at times when other are there. Go to a local cafe or local park where others of the same age may frequent.
- Establish a routine of using places such as the a swimming pool or library, so that you're likely to run into the same local people often.
- Always be careful to set an example of appropriate social behavior. For example, set an example of appropriate noise level in public places by speaking at the appropriate volume.
- As a paraprofessional, you can act as a bridge builder to help facilitate acquaintances when you're out in the community with individuals. You'll also be modeling behavior on how to introduce one's self to others.
- Other suggestions that work:

Section 4

Issues in Developing Membership

Many people with disabilities don't belong to any organizations, groups, or classes – others belong only to those specifically for people with disabilities. Often from the time they are young children, individuals spend time in "special" organizations with others who are labeled in the same way.

In segregated schools and clubs, their experience of life becomes more and more separate from others of the same age and their activities child-oriented and without any valued responsibility. As people with disabilities spend more and more time with each other they feel less comfortable with people without disabilities, and people without disabilities feel less comfortable with them. In the end everyone begins to feel that they just don't fit in and are "better off with their own kind". A vicious circle is created. For these reasons, many people with disabilities need some help or support to enable them to join and actively participate in ordinary groups and classes.

People with disabilities need people who are not staff and not paid to be with them to sponsor and support their participation and membership in organized groups- people with the same interests as themselves.

Activity 1

Discuss with the class other ways to facilitate membership. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Membership – What Helps Get it Started?

Becoming a member of an organization can help build a sense of belonging. Here are some ideas to help determine what's available, appropriate, and of interest in a particular area. These ideas can help you help someone you work with become connected to an organization.

- Making and updating a complete list of all the groups, organizations, and clubs you can think of. Brainstorm at staff meetings about additional ideas. Make a map of where these are located in your area. Give the list to parents and other staff.
- Help the individual develop the skills he or she may need to join a group that is of interest.
- Include discussions about membership in groups as part of the individual planning meeting with the team.
- Accompany the individual to several meetings that he or she is interested in until there's a comfort level for independence.
- Find someone who has an interest in the activity, class, or cause and who will accompany the individual to the meetings.

- Other suggestions that work:

Section 5

Issues in "Keeping in Touch"

Many individuals with disabilities have no basis for developing interests because they have been severely deprived of resources, relationships, and experiences. Many don't know what to be interested in because they haven't been introduced to interests. Others may have clear interests but have had few opportunities to develop them. There are also people who have had interests selected for them by staff or parents, or have become locked into interests which they once had – such as children's games or adolescent records – that they have had no opportunity to replace with more appropriate adult ones.

Other people's expectations can be a problem. One parent said, "My daughter basically isn't interested in doing anything – nobody wants to spend time with a person like that. She's happy enough with other people like herself. Trying to draw her out into the kind of social life we lead wouldn't work: in fact, it would be really unkind." The problem is not only to get beyond these very negative assumptions, but also to get beyond the very real power that parents and staff and others may exercise over the choices people with disabilities can make in general.

Social worlds provide easily accessible ways of gaining a place in community life. The potential choices are almost unlimited. What stands in the way for most people with disabilities is the lack of someone to provide the "way in", and give long-term support for participation and involvement – keeping up the subscriptions, organizing the collection, attending events. Support is critical.

Activity 1

Discuss with the class other ways to facilitate "keeping in touch". Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Keeping in Touch – What Helps?

Once relationships have been formed, it's hard to sustain them and keep them going. This is hard work. Here are some ideas to help the process.

- Talk with the individual about him- or herself. Have him or her tell you or show you what they are interested in. Think of connections these interests can make to developing relationships within your community.

- Introduce the individual to a wide variety of opportunities and activities. Get the individual to try different types of activities.
- Find people who are willing to give continued support to the individual's interest in an activity. Are there friendships that can develop out of this?
- Take time to find out what is available in your community so that you can be a resource to individuals when they show an interest in becoming involved. Be ready with ideas.
- Other suggestions that work:

Section 6

Issues in Being Part of a Family

Activity 1

Discuss with the class other ways to facilitate being part of a family. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Many children and adults with disabilities live with their parents throughout their entire lives. The family takes on a lifestyle that is not always typical, due to the particular needs of the individual. There are other individuals with disabilities who live away from their families. They sometimes have difficulty maintaining good contact with their families. This creates problems for both the individual and the other family members. In order to feel connected to the family, whether living with them or not, some active connections may need to take place.

Being Part of a Family – What Helps?

The point is not just to have a family but rather to have an active connection with family. You can help and support this connection when you:

- Ensure that administrative arrangements (like the rules and regulations in a residential setting) don't become obstacles to an active connection with family. Make sure connection and involvement by family is encouraged.
- Help the individual know his or her family history (where the family members are and where they are from) to develop a sense of connection and belonging to the family.
- Arrange for family members to share photos of various family members and have the individual share these with others, explaining who they are and their connection to themselves.
- Help individuals celebrate the traditional and special times

when families are together: Christmas, Passover, weddings, funerals, birthdays, and other times specific to the individual's cultural background.

- Support individuals in having a growing and developing relationship with their family, and at the same time respect and support the individual's need for independence.
- Make sure the individual's needs are being met, even if that means not including the family.
- Other suggestions that work:

Section 7

Issues in Having a Partner

Many people with disabilities, whether they lived with their family growing up, in institutions, or in the community, are now forming partnerships and/or marrying. This situation sometimes creates considerable concern among parents, staff, and people who plan and manage services. They are not always as helpful as they might be. One reason why it seems so challenging when people with disabilities form partnerships is that it shatters old powerful myths like "these are children that never grow up and therefore have no sexual urges". Many people have a hard enough time talking about these issues in their own lives and would rather ignore than support the union of people with disabilities. Individuals with disabilities need a lot of support in developing partnerships.

Activity 1

Discuss with the class other ways to facilitate positive partnerships. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work".

Supporting Partnerships: What Can You Do to Help?

The need for a partner has to be understood in the context of a wider need of satisfying friendships. When people have very few friends at all they may find it very hard to choose a partner. What you can do to help:

- Some special skills may be helpful (e.g., counseling, therapy, etc.) in supporting people who are making decisions about important relationships. Probably the most helpful resource though is a wide range of other close friends. Help to facilitate obtaining counseling and discussions with other friends if this seems appropriate.
- People who have many close friends with many different kinds of interests and resources are more likely to be able to make

some longer-term commitments to one person.

- When people find it very hard to communicate, it's important to try to understand what kind of a partnership they may be seeking. They may not be making typical choices that others make. Individuals in these situations may need someone to help them decide what kind of relationship would work out best for them. If you, as a paraprofessional, have spent a lot of time with the individual, you probably can offer a good listening ear and support as they work through to the best choice.
- Other suggestions that work:

Section 8

Issues in Being a Good Neighbor

Activity 1

Discuss with the class other ways to facilitate good neighborhood relationships. Write them down as the suggestions are given. Have students write these suggestions in the space that says "other suggestions that work"

Neighbors are people who live near each other. In a big city that might mean the people on your block. In a small town it might mean a much larger area. Good neighbors are friendly and helpful. They should respect one another's privacy. Privacy means not intruding in the other person's life. It means respecting confidences. *Friendliness* means offering warm, polite greetings, and generally being interested and encouraging. *Helpfulness* means doing favors for others like keeping an eye on someone's house if they were away, or helping someone with a yard project. It also means being helpful in emergencies. Sometimes a casual relationship between neighbors can become a real friendship over time. When a person with a disability who needs assistance with certain projects lives in a neighborhood, it's nice to have neighbors to turn to that will be helpful to him or her. People with disabilities often don't have this close, healthy relationship with neighbors and don't understand how these relationships work. As a paraprofessional, you can set a good example of how a person acts "neighborly" and encourage individuals to develop those kinds of attitudes and supports in the neighborhood in which they live.

Supporting Neighborhood Relationships: What Can You Do to Help?

Establishing neighborhood relationships may take some support from you. Here are some ideas to help support those types of relationships.

- Be helpful and considerate so as to serve as a good role model for how good neighbors act toward each other.
- Encourage individuals to exchange greetings with their neighbors.
- Don't act as if you must "ask permission" when people with disabilities move into a neighborhood, but instead, first make sure that good ground work is done in the neighborhood for healthy relationships to take place.
- Teach individuals that it's all right to ask neighbors to help in small ways – to lend their garden shears, or give advice on trimming the hedges. Suggest that the individual offer to water the yard for an elderly neighbor. This is good advice for a way to start a relationship.
- Other suggestions that work:

Adapted with permission from *Ties and Connections: An ordinary community life for people with learning difficulties* (1988), Roger Blunden, The King's Fund Centre.

Summary

This chapter examined issues in developing and sustaining friendships for individuals with disabilities. Specific suggestions were offered of ways that paraprofessionals can support the growth of friendships for people with whom they work. You were also given an opportunity to explore your feelings about friendships for people with disabilities. Building on what came in this chapter, Chapter Eight will discuss ways of developing social networks.

Questions to Ponder

- How do you define a friendship?
- How can you be a "bridge builder" for an individual with disabilities with whom you work? Who would you identify as a non-staff "bridge builder"?
- Consider your role as a neighbor. Does it differ from your perceptions of "neighbor" you had when growing up?
- Do you know the organizations and groups in the community? If not, how can you find out about them?

8

Chapter Eight

Developing Social Networks

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Introduction

A social network is all the people with whom an individual does activities or all the people who are important to the individual. The social network includes all the people the individual comes in contact with – such as the bus driver, co-workers, schoolmates, parents, and friends. Some contacts are frequent and some are infrequent, but they're all significant and a part of one's social network. The following quote illustrates the importance of your helping to develop an individual's network of support:

> "One candle alone has the power to give light, and we empower one another by passing the flame. If we give our gift or flame to another, our flame will not be diminished, but there will be more light. The circle of support helps us ignite and inflame the desire and will in all of us to bring out the best in each other. By working together we overcome obstacles that we are unable to change by working alone. By giving our gifts, energy, and our hearts to each other we become empowered to build a future we desire. This is the gift of the circle of support."
>
> *George Ducharme, One Candle Power*

Upon completing this chapter, you should be able to:

- Identify your support system.
- Identify strategies to find out about neighborhood groups.
- Demonstrate the benefits people in a social network get from one another and give to one another.
- List ten considerations when building a relationship.
- Identify facilitator do's and don't's.

Section 1

Social Networks

To help an individual increase his or her social network, watch how long it takes for someone to become important to the individual. Observe how much contact takes place between the individual and others before they seem to become important to him or her. Does the individual "warm up" to people quickly? Are there some types of people he or she is more drawn toward? Is the person actively involved in a social setting or on the sidelines watching others?

Noticing these and other signs can help you understand the individual's interests in a social setting as well as his or her need for support.

Activity 1

Have students fill out the handout "Looking at My Support System" either as a homework assignment or in class. Have them discuss who in their own lives makes up their support system. Discuss this as a group. Tell students to use this activity to help prepare individuals they work with for the next activity.

Activity 2

Tell students you're going to walk through this next activity in the same way they could do it with individuals with whom they work. Say to students, "Who are the people in your life who are important to you? Start with yourself in the center ring. Fill in the names of people who are the most important to you in the next ring, the next level in the next ring, and so on, until the outer ring includes acquaintances or people who are on the

[*Continued on p. 83*]

Looking at My Support System

What do I already have?

Name	How am I supported?	Is it what I want?	Is it enough?

What do I want? ***More support – or a different kind of support?***

- **At Work**

Type of support?	*From whom?*

- **At Home**

Type of support?	*From whom?*

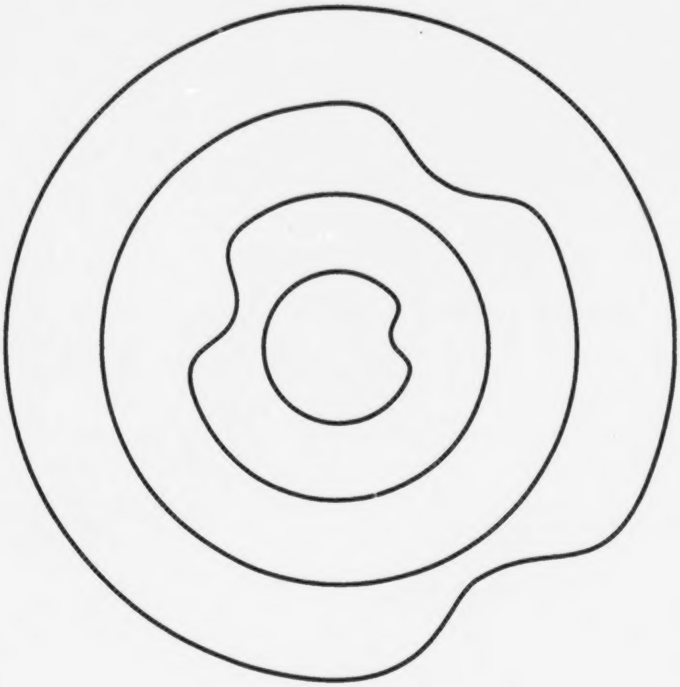
- **From Friends**

Type of support?	*From whom?*

There are various types of possible support: trading support, giving feedback, nurturing, playing, getting together, inspiring, teaching, empathizing, sharing job or career resources, advising, listening without judgement, being there, etc.

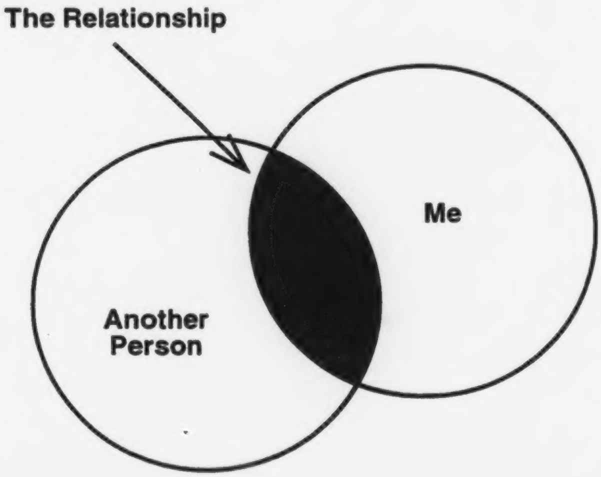
Draw in the rings below. You go in the center ring. Who are the people in your life who are important to you? They go in the ring next to you. In the next ring go people in the next closest group to you. Continue until you reach the outermost ring.

Notice the "notches": these are the places people fit. It's that person in each ring that could be closer to you with some effort. What steps can you take for him or her to be closer?



I Get Support from My Relationships with Others

I can identify the persons in my personal support network and the areas in which they will be involved.

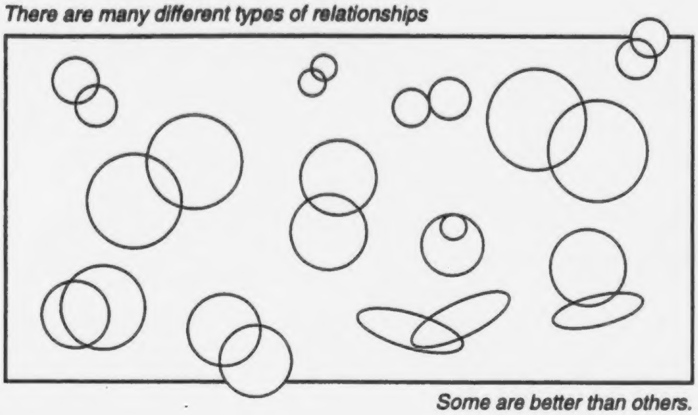


[*Continued from p. 82*]

periphery in your life. Notice the notches in each circle. Each notch is a place for a name of someone in that ring you would like to be in a closer ring. Write there name there. What can you do to work toward that with that person? How can you relate these ideas to helping individuals with disabilities you work with to work toward closer relationships?" Tell students they can use the second blank circle to do this same exercise with an individuals you are working with (or will in the future) who needs to improve his or her relationships with others.

Activity 3

Have the students look at and discuss the figures "I Get My Support from My Relationship with Others" and "My Personal Support Network". Discuss the circles that overlap and how relationships are all different from each other. Discuss how these could be used to help people with whom students will work. As an out of class assignment, have students work through this worksheet in one of two ways, depending on the nature of the class. If most students are currently working, have them do this exercise with an individuals with whom they work. If not, have them do the activity with a friend or neighbor.

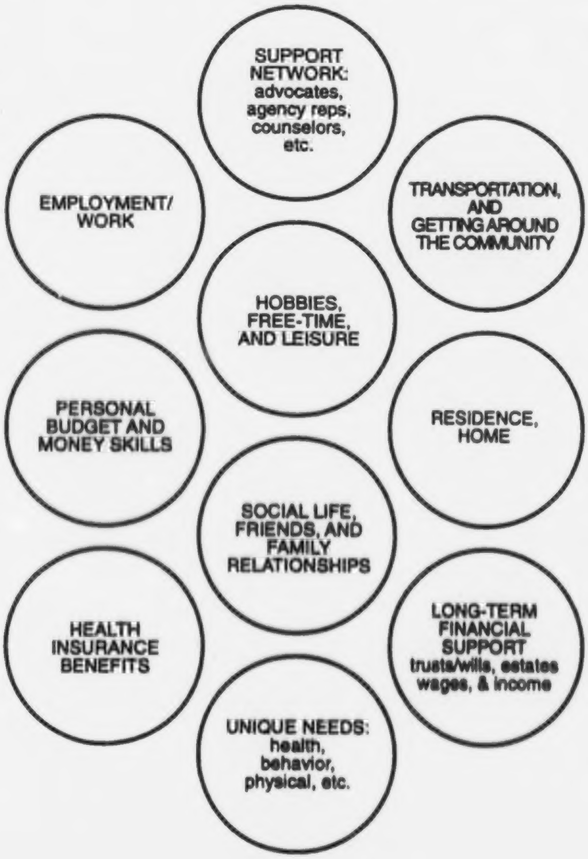


There are many different types of relationships

Some are better than others.

My Personal Support Network

I can identify the persons in my personal support network and the areas in which they will be involved.


SUPPORT NETWORK: advocates, agency reps, counselors, etc.
EMPLOYMENT/ WORK
TRANSPORTATION, AND GETTING AROUND THE COMMUNITY
HOBBIES, FREE-TIME, AND LEISURE
PERSONAL BUDGET AND MONEY SKILLS
RESIDENCE, HOME
SOCIAL LIFE, FRIENDS, AND FAMILY RELATIONSHIPS
HEALTH INSURANCE BENEFITS
LONG-TERM FINANCIAL SUPPORT trusts/wills, estates wages, & income
UNIQUE NEEDS: health, behavior, physical, etc.

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Finding My Friends

Use this exercise to plan and discuss opportunities for making friends and developing relationships. After filling this out together, have the individual fill in his or her circle of friends, including those he or she would like to become closer to.

What do you do to make friends?

What I Do | Who I'd like to know better

In my neighborhood

At work

In school

In my place of worship

In activities

Activity 4

Have the students complete this chart using themselves. Tell them this is also an activity they could use with individuals to help them discover others in their lives they'd like to know better.

Activity 5

Go through this list and with the class and discuss how important it is for paraprofessionals to have a network and supply of ideas when helping individuals learn how to network and become involved in their communities since most individuals won't have many ideas of their own. Ask students to add to the list, from their experience.

Finding Out About Neighborhood Groups

If you're looking for ways to include individuals you work with in neighborhood activities or looking for activities for individuals to become involved in, here are some ideas:

- Read meeting schedules found in the local newspaper.
- Collect directories of community organizations from the public library or ask the United Way organization for a listing, or seek out self-help directories.
- Talk to people at local institutions such as parks, recreation centers, churches and community centers and ask what groups schedule regular meetings in their buildings.
- Conduct a phone survey of local residents and ask, "In what do people participate in this area?" You may first want to send a letter to residents in a selected area about your interest in area activities and explain that a phone call will follow the letter to ask for their suggestions of area activities.
- Ask the librarian about local meetings and the times they meet. Many meetings are held in the local library.
- Ask for group names and meeting times. Many meetings are held at local parks.
- Call local bowling alleys and ask about leagues, etc.
- Call churches and ask what local meetings are held in their building, the types of groups, and the times they meet.

Adapted with permission from *Getting Connected: How to Find Out About Groups and Organizations in Your Neighborhood* (1988) by Kathy Nakagawa, Center for Urban Affairs and Policy Research, Northwestern University and Department of Rehabilitation Services, State of Illinois, 2040 Sheridan Road, Evanston, Illinois 60208; Telephone, 312/491-3395.

Show Transparency 8.1

What Friends Do For Each Other

Here are some benefits that people in a social network get from one another and give to one another in social relationships:

- **Information:** People in a social network give and get information from one another. For example: "Do you know any good plumbers?" "Where did you get those shoes?"
- **Feedback:** People in social networks give and get advice from each other. For example, it might be technical – having to do with work – or personal, or relating to social skills or manners.
- **Assistance in making major life decisions:** People in social networks help each other make big decisions about events such as career changes, moving, marriage, or school plans.
- **Emotional support:** People in social networks help each other when happy and sad situations affect their lives. Some of those situations might be death in the family, unhappy relationships,

problems with children, or celebrating happy events like births and weddings.

- **Material aid and service:** People in a social network help each other out in small and big ways. For example, someone may care for a neighbor's pet while out of town, a friend may loan money until pay day, and a neighbor may loan tools or a ladder for a project.
- **Access to others:** People who are part of a social network are introduced to other friends and may extend their base of friends at all levels. A friend may invite another to a party or social gathering where new people and potential friends are met. The neighbors may have a block party where one meets new people.
- **Companionship:** People who are part of a social network have others they can plan activities with and have as companions.

Adapted with permission from *Social Support Manual* (1989) by J. Stephen Newton, Neighborhood Living Project, Specialized Training Program, 135 College of Education, University of Oregon, Eugene, Oregon 97403-5215.

Levels of Support to Help Improve Social Life

The following are some ideas to offer support to individuals to help improve their social lives. These ideas may be useful to you in helping individuals establish and maintain relationships.

- Write social life objectives in the IHP/IEP/IFSP.
- Use staff meetings to notice and assign tasks to each other that may naturally result in improved social experiences for the individual throughout the course of his or her day.
- Set weekly goals for socially integrated activities. Break down those ideas into small steps so the individual is always working on a manageable piece of a social life skill area.
- Rotate the responsibility among staff members to be the social director for a week. That person planning social activities for the week can be non-staff people (volunteers), kitchen staff, office staff, as well as paraprofessionals and teachers, counselors, etc.
- Encourage individuals and their families (or group home leaders) to volunteer to have an in-home social activity. For example, someone may host a Monday night football party get together, another may host a walk around the area lake or neighborhood.
- Help individuals join local clubs, organizations and churches that share his or her common interests. Then help the individual focus on getting involved. Help in the organizational process (such as registration fees, paper work, finding the location and time, arranging transportation) until he or she is

Activity 6

All these reasons for a social network should be discussed. Discuss what life would be like for the students if they had no, or very little, social network. Then discuss the difficulties many persons with disabilities have in relation to these difficulties. Explain that often individuals with disabilities don't have as many opportunities to tap into sources for building social networks. This creates feelings of uselessness and isolation. This makes it even more important for the paraprofessional to work as a facilitator for friendship and social network building. Everyone of the above avenues for social network building can be opportunities for paraprofessionals to help individuals tap into systems to make friends.

Have students read and discuss the handout entitled "Making Contributions" in Appendix L. Discuss the ideas for students to help encourage individuals to get involved in neighborhood & community activities to help create and develop their own social network.

settled into the activity.

- Explain and encourage the idea of reciprocity. For example, as part of friendship, first I do something for you (i.e. buy you lunch) then you do something for me (i.e. you take me out to lunch). Explain that to keep friendships alive and growing, people have to take turns calling each other and making plans together.
- Accompany the individual on the first meeting or first activity into the community to help facilitate ease and comfort for him or her and the community people. Help them understand each other. If you work with children and have made suggestions about activities to the parents, offer to attend the first activity with the parents and the child.
- Find out the individual's interests. Introduce him or her to people with similar interests. Friendships are usually based on similar interests. Sometimes people don't know what their interests are. They need to try different activities to find out what appeals to them. ("How do you know you won't like it if you haven't tried?")
- As a paraprofessional, you also need to build your own social network and social integration system through community activities. Activities are more likely to be spontaneous if you (or someone else on staff) have had prior involvement in the activity your are encouraging. Regular activities that are done over and over are reinforcers for friendships (fast food restaurants, bowling, concerts, movies, etc.).
- Teach the individual to independently go out and do activities (as much as possible) that will facilitate his or her own social life. For example taking the bus, biking, setting up own arrangements and plans, shopping alone, going to recreational areas alone, all create a sense of independence and enable the possibility of friendships developing in a natural way.
- Decrease or replace behaviors that compromise social life. Help the individual improve his or her ability to have a better social life by teaching him or her acceptable social behaviors.

Adapted with permission from *Social Support Manual* (1989) by J. Stephen Newton, Neighborhood Living Project, Specialized Training Program, 135 College of Education, University of Oregon, Eugene, Oregon 97403-5215

Role-play Situation

Pretend you're running a weekly staffing and discussing the social situation Toby is in. Use the "Levels of Support to Help Improve Social Life" ideas on the previous pages to help come up with some ideas. Do this in small groups, then share your solutions with the entire class.

Situation

> The school psychologist, the nurse, the regular classroom teacher, the paraprofessional, and the physical education teacher get together for a team meeting every Tuesday at Harley High School to discuss Toby's progress in all areas. On this particular Tuesday, the physical education teacher states that he has been watching the interaction with Toby in gym class, the locker room and in the hallways. Because Toby weighs 220 pounds and is a star on the football team, the guys always want Toby on their team in class, but they seldom interact with Toby any other time. Toby has appeared especially dejected lately and the physical education teacher talked to him about it last Friday. Toby says he wants to make friends with the guys, but they're always too busy for him, or ask him to do impossible things with them, like drive them to a party (Toby works night and doesn't drive). The coach would like to facilitate some friendships for Toby. Role-play the situation to find your group's solutions to this dilemma.

Feel free to adapt the situation, if needed, to be more suitable for your group.

Ten Considerations When Building Relationships

All relationships follow the pattern below to some degree or another. When working to facilitate friendships for, and with, persons with disabilities, some of these considerations may be hard to comprehend. You may need to do some direct teaching of these ten considerations and it's important for you to know and understand this.

- Relationships are always possible. There's potential for relationships to form but never certainty that they will.
- People have a range of relationships from acquaintances to lovers which makes their lives complete and integrated.
- There's no real logic to how relationships develop and progress. Painful struggles can be a sign of great growth. Conflict is normal and okay. Absences do not necessarily mean the relationship is over.
- Rejection is part of the relationship making process. It's typical to meet people and decide you do not choose to make friends with them.
- Relationships build slowly and strengthen over time. They're full of ups, downs and struggles.
- Relationships start from small beginnings and can't be determined from only one meeting. Trust takes time to build and friendship is built on trust.
- Experiences, opportunities, and relationships are all connected. The more opportunities a person has, the more

Activity 7

Have the students break up into small groups and "pretend" to be running a weekly staffing where they're discussing the social situation in the following role-play. Have someone record the discussion. The group "team meeting" should come up with some IEP/IHP long-term objectives for this situation and some short-term, or weekly goals for which to strive.

Activity 8

Explain to students that the importance of understanding this list of "Ten Considerations for Building Relationships" is in the fact that all relationships with all people follow this pattern to one degree or another. When working to facilitate friendships for and with persons with disabilities it's especially important to remember that there might be some difficulty in some of these considerations. Some individuals may not understand the subtitles addressed here in establishing relationships and may need to be taught these ten steps very deliberately as a means to help facilitate relationships. Paraprofessionals should discuss these ten points as a group and brainstorm ways they would "teach" these tips to individuals with whom they work.

chance they have for relationships.

- Building relationships takes a lot of self-confidence and time. Be patient.
- Relationships are always in a state of growth.
- Relationships do not depend on a person's abilities and attributes, but on comfort and ease between two people

Adapted with permission from *Leisure, Integration, and Community* (1992) by P. Hutchinson and J. McGill, Concord, Ontario: Leisurability Publications, Inc.

Facilitator *Do's* and *Don't's*

These are important guidelines for you as a paraprofessional to know when helping to facilitate friendships.

Don't's

- Choose friends for individuals.
- Decide who is appropriate and who is not appropriate to be a friend.
- Structure activities to meet their needs over the interests of the individuals.
- Decide for individuals what their interests will be.
- Assign a "friend" to someone and then feel they have helped develop friendships and their job is done.

Do's:

- Have a positive relationship with the individual (this models appropriate friendly behavior).
- Have skills in including individuals in groups so they can develop a sense of what it's like to be a part of a friendly group.
- Support the process of finding and making friends by emphasizing the individual's strengths.
- Act as an unobtrusive supporter and facilitator.
- Help plan appropriate interest related activities.
- Encourage the individual to advocate for personal needs in a relationship.
- Offer and encourage one-on-one experiences with peers to develop confidence in relationship building skills.

Adapted with permission from *Connecting Students: A Guide to Thoughtful Friendship Facilitation for Educators and Families* (1992) by C. Schaffner & B. Buswell, PEAK Parent Center, Inc., Colorado Springs, CO 80918.

Activity 9

Hold a discussion with students about the do's and don't's of facilitating friendships. Emphasize that there's a delicate balance between being proactive and taking over the relationship development and the paraprofessional needs to support the activity but not force friendships.

Summary

This chapter defined a social network, discussed ideas for developing social networks, and offered you an opportunity to identify your support system. As a paraprofessional, you're in a position to support people you work with as they develop their social network. Social networks empower one another to build futures that they desire.

Questions to Ponder

- What new information did you gain from doing the activity "Looking at My Personal Support System"? How could you incorporate this activity for individuals with whom you work?
- People in social networks give and receive a variety of things: information, feedback, assistance in making life decisions, emotional support, material aid and services, access to others, and companionship. Can you identify people that give you these types of support? Can you identify people that *you* give these types of support?

9

Chapter Nine

Facilitating Friendships

93 Introduction
93 Section 1 How to Facilitate Friendships
95 Summary
95 Questions to Ponder

Introduction

Knowing how to support individuals with disabilities with whom you work to start friendships can strengthen the network of support and the entire empowerment process. This chapter discusses key strategies you can apply and build on in individual situations.

Upon completing this chapter, you should be able to:

- Identify strategies that could assist people with disabilities to start friendships.
- Identify activities to facilitate friendships.

Section 1

How to Facilitate Friendships

In many cases, you – as a paraprofessional – may be put in a situation where you can best facilitate friendships between two individuals. You may see the spark of a possibility for a friendship in a work setting, school setting, a neighborhood or community setting, or a residential setting. If you take the initiative to start a friendship for two people, they may be able to continue the relationship with your support. The following suggestions and activities may help you in your efforts to help individuals with disabilities start friendships.

- Survey the situation. Look at the various social and work situation the individual will be in. Who does the individual seem to gravitate towards (or visa-versa)? Is he or she lonely? Does he or she talk about anyone particular in the neighborhood? How does the individual communicate with others? Is there someone he or she makes more of an effort to be with? Does he or she seem to be angry or upset if unable to get or keep the attention of someone. *These might be messages about possible friendships that could be developed with some facilitating on your part.*
- Review the individual's day. Think of times throughout the day that these possible friendships may be nurtured. Are there times that you could facilitate a natural type setting for two friends to get to know each other better? *Timing is everything. What key times can you plug in friendship facilitation?*
- Estimate how much facilitation will be needed. How independent is the individual? How willing is he or she to self-advocate and reach out to establish his or her own relationships? When does the individual really need your help to facilitate relation-

Activity 1

Ask students to give examples for each of the eight steps to facilitating friendships from work or personal experiences. Discuss these as a group. Ask students to discuss these questions: What's the most difficult part of facilitating friendships? How do you think you'll know when to back out and let the people handle the friendship on their own? How can you "find opportunities" without getting overbearing? How can you accommodate situations without being patronizing?

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Activity 2

Have students brainstorm in small groups and come up with additional activity ideas, then have each group share their ideas with the whole group.

Activity 3

Paraprofessionals may want to look at the ideas in the "Conversation Start-Up Kit" found in Appendix M as ideas to use to role play situations with individuals to help them get started in a conversation. Paraprofessionals can practice ideas for starting conversations with individuals in various circumstances as a way to initiate contact that can lead to relationships.

Activity 4

Additional resource ideas to help facilitate friendships: Students should read and discuss the ideas in the handouts "A Catalogue of Ideas", "Doing Things Together", and "Community Resources" located in Appendix N.

ships? (It may be only at certain times in certain circumstances.) Figure out how much help is needed. *Don't be too intrusive. Offer only the level of support that is needed.*

- Determine what you can do that will be most helpful to specifically facilitate the friendships and make a plan. Think about whether you should help in finding opportunities, in interpretation, or in accommodation. At what level is the individual's relationship development? *Start where the individual needs the most help.*
- Think about who would be the best facilitator in the situation. Each situation will be different. Who's the most logical person to assist in each situation? When you get together in your team meetings, discuss who, based on relationship with the individual, personality, and job assignment, is best in handling each facilitation. *Use the most logical staff person to facilitate based on individual situations.*
- Explore and assess ways to use natural everyday situations to create and develop relationships. Often the best opportunities for friendship development are right under your nose. What is going on in the individual's everyday life? How can you capitalize on that to facilitate friendships naturally. *Sometimes the best opportunities are also the simplest.*
- Follow-up on situations. Relationships have their ups and downs. Once you've helped get a relationship started, you need to be available to monitor the progress and support the individual in those ups and downs. This will help the individual to become confident and understanding about relationship development so he or she can become independent in developing friends in the future. *Continue to be there for the individual during the development of the friendship.*
- Disappear as soon as you can. As soon as the friendship has taken on a life of its own, back away and let it develop without your facilitation. At the same time, let the individual know you care and are there for support. *Once the relationship is established, back out.*

Adapted from *Connecting Students: A Guide to Thoughtful Friendship Facilitation for Educators and Families* (1992) by C. Schaffner & B. Buswell, PEAK Parent Center, Inc., Colorado Springs, CO 80918.

Activities to Facilitate Friendships

Here are some ideas you can use to help facilitate friendships. Think of each person you work with individually: which of these would work in your experience and understanding of the unique needs of each person?

- Give individuals opportunities to show off their strengths to the others in the group.

- Tell others about special interests or talents of individuals in the group.
- Show positive ways to deal with unpleasant situations that an individual may create to show the group coping skills for the individual's behavior.
- Be available to demonstrate strategies, answer questions, interpret situations, and answer concerns as needed.
- Help individuals learn how to communicate well with others by serving as a role model for good communication and interaction with others.
- Encourage individuals to communicate honestly, whether they are telling about fears, concerns, questions, or issues.
- Encourage discussions about friendships in the natural setting of work or play. Talk about what friendship involves so that others can talk openly about their friendship experiences.
- Brainstorm together for solutions to issues and problems between friends.
- Offer individuals times to honestly talk about their strengths and weaknesses.
- What other activities would you encourage to facilitate friendships in your setting?

Adapted from *Connecting Students: A Guide to Thoughtful Friendship Facilitation for Educators and Families* (1992) by C. Schaffner & B. Buswell, PEAK Parent Center, Inc., Colorado Springs, CO 80918.

Summary

This chapter offered suggestions and activities that you as a paraprofessional could use to help individuals with disabilities start friendships. These included surveying the situation; reviewing the person's day; identifying how much facilitation is needed; exploring ways to use natural situations; following up; and disappearing as soon as possible.

Questions to Ponder

- Have you ever helped someone with a disability start a friendship? What strategies were successful and how could you tell? What about strategies that didn't work? How could you tell?

10

Chapter Ten

Planning for the Future

97 Introduction
97 Section 1 Promoting Friendships and Self-Advocacy Through Futures Planning
103 Summary
103 Questions to Ponder

Introduction

As you work with individuals with disabilities, encourage them to self-advocate, and facilitate the development of friendships, you're empowering these individuals to make their own choices about the lives they want to lead. You help them to have the rights to which all people are entitled. It's important to end this module on promoting self-determination and facilitating friendships and socialization skills with a discussion about current trends in planning that will lead to individuals who are more empowered and in control of their own lives and making their own choices about who they choose as friends and to associate with.

Upon completing this chapter, you should be able to:

- Describe MAPS and Personal Futures Planning.
- Identify do's and don't's of person-centered planning.

Section 1

Promoting Friendships and Self-Advocacy Through Futures Planning

There are two planning strategies that also help ensure, in a more structured way, positive empowerment and planning for the individual's future. One strategy is called MAPS (Making Action Plans) and the other is called PFP (Personal Futures Planning). Both utilize the people in the individual's life who know and care about him or her to identify and move toward desired goals. These two strategies on planning for individuals with disabilities are unique because they include not only professionals, but also the individual, family, friends, and peers without disabilities. MAPS is generally associated with students, and PFP with adults, but each can be used in a wide variety of situations. Each is an ongoing process that builds on the individual's capacities.

Activity 1

Tell the students there are many specific strategies used for planning the future with individuals with disabilities. These are just two, but they illustrate the importance of individual self-advocacy.

MAPS

MAPS uses a two-step process:

Show Transparency 10.1

- Key questions are asked to create a picture of the person and to establish a direction for the group. Those questions direct the group about the needs, interests, abilities, and desires of the individual.

- Certain people are targeted who will develop specific action plans. These people are selected based on their knowledge of the individual and their expertise in the area where the plan will be developed. For example, if the individual's MAPS states he or she needs to develop social skills in the community, a recreation specialist may develop that part of the plan.

After the plan is made, alternatives and adaptations are made as needed. Because Personal Futures Planning is becoming very popular as a method of planning with individuals with disabilities today, we will focus primarily on this strategy.

Activity 2

Have students read and discuss the seven steps of Personal Futures Planning. Discuss the implications of Personal Futures Planning on the IEP/IHP process. This is required in the transition planning process. Paraprofessionals can be instrumental in gathering this information and sharing it at the individual's planning meeting. Discuss the Personal Futures Planning process and the impact it can have on the process of empowering individuals to be their own best advocates. How can Personal Futures Planning effect the individual's ability to develop relationships?

Show Transparency 10.2

Personal Futures Planning: Steps

Personal Futures Planning creates a personal profile of the individual's life. There are eight steps to the personal planning: the details and sequence of each step vary for individuals, but each process includes the following components:

Step 1: *Identify Capacities*

- Map out relationships: Who's important to the focus person?
- Map places: What are the patterns of community life for the person?
- List personal preferences: What gifts (special talents or abilities) does the person possess?
- Clarify personal dreams and desires: What goals does each individual have for him- or herself?

Step 2: *Identify a Planning Group*

The individual asks the people he or she would like to ask to work together in his or her planning meeting. These people agree to meet on a regular basis to learn together and plan for things to happen for the focus person. They use a relationship map for this planning.

Step 3: *Clarify a Personal Future*

The person and his or her group work together to clarify goals so they share a common vision of what they are trying to accomplish by working together.

Step 4: *Identify Obstacles and Opportunities*

Obstacles, fears, and barriers to desirable futures are identified. These barriers offer a focus for problem-solving and for networking with other groups who face similar barriers.

Step 5: *Generate Strategies*

The groups meet regularly (about once every six weeks) to review what they have learned, accomplished, or encountered as new barriers or opportunities. Groups brainstorm to generate new strategies and directions for future activity.

Step 6: ***Make Commitments***

Following each review and brainstorming session, individual members make commitments to work on specific strategies. Members choose the strategies they have the energy to work on.

Step 7: ***Take Action***

Group members take action. Many groups focus initially on learning more about community resources, program models, and other barriers they face.

Step 8: ***Reflect on What the Group is Learning Together***

Every meeting is a time of reflection, but periodically (about every six months) the group will meet to look again at "the big picture," to re-focus, and to summarize their accomplishments.

Adapted from *One Candle Power: Building Bridges into Community Life for People with Disabilities* by P. Beeman, G. Ducharme, & B. Mount, Communitas, Inc., P.O. Box 374, Manchester, CT 06040; telephone 203/645-6976

In Planning Futures, Remember...

In order to help sharpen the vision and recognize capacity in everyone, remember the following when planning futures:

Do	Don't
• Look and listen long enough to find the capacity	• Concentrate on labels
• Seek abilities not commonly valued in our society today (i.e. the ability to be present or to bring people together)	• Be put off by visible evidence of labels
• Focus on the abilities of all people in the support system	• Prejudge a person because of a label
• Focus on the unique opportunities of each association in a neighborhood & community	
• Build on strengths that an individual has, not the weaknesses	• Don't dwell on disabilities

Adapted from *One Candle Power: Building Bridges into Community Life for People with Disabilities* by P. Beeman, G. Ducharme, & B. Mount, Communitas, Inc., Manchester, CT 06040.

Activity 3

Stress the following Do's and Don'ts about futures planning and looking at the abilities and capacities of the individual.

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Futures Planning: Scenarios

To become more familiar with the process of futures planning, read the following three scenarios and then, in class, discuss the benefits of futures planning for each person.

Scenario I: Gordon

Gordon is a handsome seventeen-year-old man with a good sense of humor who really enjoys sports. He has been classified in the moderate–severe range of mental retardation, has had some serious medical problems beginning at an early age, and has some serious behavior problems such as hitting others.

The persons involved in his planning group included his mother, special education teacher, and social worker. His father was either unable or unwilling to attend meetings. Gordon has no siblings and no interactions with neighbors or friends in his area.

Gordon's mother had been complaining about various things regarding Gordon for a long time. As a result of the futures planning process, she started really becoming an advocate instead of just a complainer. She also started to get real support from other members of her family, instead of just sympathy.

The long-range dreams for Gordon and his family included finding a trustworthy doctor, finding a respite program where the parents could be away from home on vacation for two to three weeks at a time, and finding a friend for Gordon for his after-school hours.

Gordon's mother started to take on more responsibility and learned to ask for help when it was needed. Because of the need for respite care, she began a letter-writing campaign to the county commissioners. She wrote, but also got her relatives and people in the group to write letters about the lack of respite funds. Inspired by these efforts, the social worker also started looking into county resources. As a result of both these actions, the county opened up respite funds again. Gordon has been receiving respite care at least one weekend a month now for over a year.

It used to be rare for Gordon's mother to take him out to events. But since the futures planning, his mother has taken him out more into the community. One evening a month, they attend adaptive community recreation sessions in which people play guitars and/or banjos for interested audience members, whether disabled or not. Information on other community friendship and recreation programs has also been sent to Gordon's mother, and work is continuing on the ongoing challenge of finding friendships outside school.

During times that have been stressful with certain doctors and other medical personnel, the school physical therapist has gone with Gordon and his mother to medical and orthopedic appointments to support the mother. Gordon's communication skills have also been re-evaluated to help him experience more success

Activity 4

To become more familiar with the process of futures planning, have students read the three following scenarios. Although these three situations deal with adult individuals, stress that futures planning can be done at all ages. After students read the scenarios, discuss the benefits that the futures planning brought to the lives of Gordon, Cindy, and Helen.

in letting his needs and wants be known.

As Gordon is experiencing more success in his school activities, his mother has become much more positive. She has learned much more about asking for and getting support, and about active advocacy for her son.

Scenario II: Cindy's Wheels

I've had the privilege of working with Cindy and participating in the development of her personal futures plan. Cindy is an adult who has cerebral palsy, and a degree of borderline retardation which sometimes means she also carries that label – but sometimes she doesn't.

Cindy is a strong advocate for herself, and – long before it was popular – she pushed the system (and herself) to move into her own apartment. Ten years ago, she put herself through Courage Center's apartment training program and since then has been living in her own apartment with a personal care attendant. Some time ago, Cindy achieved for herself many of the things that the system is just now seeking for people with disabilities: an independent living situation, full integration in the community, and time to spend with friends and loved ones who care.

At her initial futures planning meeting, Cindy told us that she had tried to get a new motorized wheelchair the year before but her request had been rejected. Her old chair was ten years old, broke down a lot, and was showing definite signs of wear. It seemed reasonable for her to have a new chair. I speculated that Medical Assistance probably rejected her request due to an omission or an error in the application process.

Her planning group discussed other options than a new chair. A friend of Cindy's who also uses a motorized chair talked about the possibility of buying a new motor if Cindy's request was rejected again. We realized that what was really needed was for someone to be willing to dig through the red tape for her. I felt that was where I could be useful. Even though I knew nothing about the process, I knew enough to start asking questions.

I soon learned that what Cindy really needed was a medical expert to assess her chair, her positioning, and her needs. After all of the assessments, the expert would formally submit the request for the new wheelchair. In order to begin the process, it was necessary for her own physician to make the necessary referrals. This entire process was lengthy and took nearly a year to complete.

Members of the planning group supported her in a variety of ways during this time. We talked with her physician and the positioning clinic. We made appointments for Cindy, arranged for her to be there for her appointments, and sometimes even accompanied her. During this time, I talked to companies that manufacture motorized wheelchairs and had their sales representatives attend some of the appointments with Cindy.

It was exciting for Cindy to pick out the features of her new chair: the color and style of the frame, the color and fabric of the upholstery, and the type of foot rests. It wasn't difficult to see the group's enthusiasm as we ventured into this project. It was so contagious that the sales representative for the wheelchair manufacturer got caught up in our enthusiasm and called us the very moment he heard that the application for the new wheelchair was approved. "I am putting the order in today! Just thought you would like to know." We had a mini-celebration upon learning this news – "mini" because Cindy still had to wait for eight weeks before her new chair would be delivered.

When the chair finally arrived we had a party to celebrate its arrival and to congratulate ourselves for hanging in there. It's a wonderful chair which Cindy says gives "a smooth, quiet and dependable ride!"

Scenario III: Helen's Life

Family is and always has been the central focus of Helen's life. She has an excellent relationship with her mother, who lives in Minneapolis. Her brother lives with their mother, and often takes Helen under his wing, taking her various places. Her sister has also always been a strong ally.

At the time we began dreaming of an "ideal vision" for Helen's future, she was living at a state regional center. She was involved in a supported employment job in the community and loved her work. Helen participated fully in the futures planning process and let those of us in her planning group know what she wanted to accomplish in her life.

Her own vision for the future includes living in her own apartment close to her family. She wants a dog to care for and easy access to transportation. Being close to shopping malls and recreational activities is important. She wants to cook her own meals and have enough money to buy the things she needs. Church is very important to Helen and she hopes to be able to help a pastor with church activities. Her dreams for her future are fairly ordinary and she doesn't expect too much.

When the staff started working on moving Helen out of the treatment center, they were unable to move her directly into her own apartment. Since her plan was developed, Helen's left the regional treatment center and moved to a group home in southwestern Minnesota. Fifteen people with disabilities live in the home and there are two people in each bedroom. Helen has a job at a motel in town which she likes very much.

The futures planning process gave Helen the chance to say what *she* wanted. The process gave direction to the placement process, in terms of what's important to Helen. It put her dreams to paper and some of what she wanted has happened. Without the process, what Helen wanted wouldn't have been articulated.

Helen's sister also lives in her new home and the two women enjoy each other's company. They have re-established their relationship and are now the best of friends. They frequently picnic and enjoy a variety of activities together. A local taxi provides them access to excursions into the community and shopping at the local mall. Helen visits her mother occasionally, using the bus to get to and from Minneapolis. There are many churches near her home where Helen can get involved. She doesn't yet have a dog, but hopefully this, too, will become a reality.

Helen seems very happy with her move from the regional center to the group home. This is only the beginning of the movement toward Helen's dream. The planning group has given input to the group home staff on her visions. Helen's mother wants to keep the planning charts up in her house. With the continued support of Helen's planning group, there is good reason to believe all her visions will be realized.

These three scenarios are adapted from ***Listen, Lady, This is My Life: A Book About Futures Planning in Minnesota,*** by A. Amado, developed by the Minnesota Governor's Planning Council on Developmental Disabilities

Summary

Two types of person-centered planning were discussed in this chapter: MAPS and Personal Futures Planning. The person-centered planning encourages individuals with disabilities to be empowered to take more control of their lives and to have their dreams identified and supported. As a paraprofessional working with people with disabilities, you could encourage and support this type of person-centered planning.

Questions to Ponder

- Have you ever participated in a person-centered planning meeting? How did this process differ from other planning meetings you've attended?
- What are ways you could encourage using a person-centered planning process with individuals with disabilities with whom you work?
- What benefits do you see in using person-centered planning? For whom?

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Appendix A
The Dignity of Risk

By a parent whose son is in a supported work program in Richmond, Virginia

What if you never got to make a mistake?

What if your money wasn't always kept in an envelope where you could get it.

What if you were never given a chance where you could do well at something?

What if you were always treated like a child?

What if your only chance to be with people different that you was with your own family?

What if the job you did was not useful?

What if you never got to make a decision?

What if the only risky thing you could do was to act out?

What if you couldn't go outside because the last time you went outside it rained?

What if you took the wrong bus once and now you can't take another one?

What if you got into trouble and were sent away and you couldn't come back because they always remember you're "trouble"?

What if you worked and got paid forty-six cents an hour?

What if you had to wear was your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of the grocery shopping but weren't allowed to do *any* because you weren't able to do *all* the shopping?

What if you spent three hours every day just waiting?

What if you grew old and never knew adulthood?

What if you never got a chance?

From *Changing Expectations/Planning for the Future: a Parent Advocacy Manual* by Dorothy Sauber, ARC Minnesota, Minneapolis, Minnesota.

Appendix B
Family Empowerment

By Rud Turnbull

Once upon a time, a decade ago,
Two families found a way to go
Through life with pain. or else with gain,
Despite being almost the same.

"There's not much we can do, except be tossed
Hither and thither, and hope what we've lost
Can be recouped, just a little bit.
That's sufficient, more than a whit."

So said the one, whom we'll call *Doubt.*
They piqued the interest of the family *About.*
Doubt was skeptical, a powerless clan.
About was determined, a strong woman and man.

"Disability motivates. It's our spur.
It causes change in us and in her.
Our daughter's world is different in kind.
But some skills we have, and others we' ll find."

Said *Doubt,* power out of their range,
"You'd better accept things you cannot change."
Answered *About,* putting on armament,
"We disagree. We're feeling empowerment."

Over the years, *Doubt* never learned what to do,
While *About* changed themselves and systems, too.
Doubt took a road traveled by some few.
About chose a path that has helped even you.

With doctors and teachers *About* raised their voice,
"Work with us! Please honor our choice!"
And as they lived in their little town,
Strengthening ties began to abound.

Neighbors and friends, and clergymen too,
All quickly learned what they could do.
They surrounded *About* with their generosity,
Providing a different social security.

In my very simple and none too elegant ditty lie most of the elements of the debate on empowerment. How useful is a poem about empowerment? It has two uses. First, like many good poems, it distills the essence of a complex concept. After reading it, the reader *needs* to know nothing more. Second, it lends itself to analysis that further explains a complex concept. After reading the poem, the reader who *wants* to know more about the concept may dissect the poem and, by discovering nuances in it, achieve a deeper understanding. Here, I begin with the elementary and move to a more sophisticated understanding of empowerment.

Two Different Approaches

Let's begin by considering the poem 's two families. The *Doubt* and *About* families each have a child with a disability. There is where their similarities end, however. *Doubt* is not motivated by the fact of disability. *About* is. *Doubt* accepts things pretty much as they are, content to be reactive. *About* acts on that motivation by identifying their resources and vowing to find others; they become proactive.

Choosing the path of least resistance, D*oubt* makes very little difference in their own family's life, much less in any other family's life. *About* opts for the more difficult path and thereby makes a powerful impact for themselves and others, too.

Elements of Empowerment

The essential elements of empowerment are present in A*bout* but not in *Doubt*: *motivation*, plus *action* that uses inherent *skills*, develops other *resources*, and *impacts* one or more situations.

Empowerment is also a *process*. *About* experiences empowerment immediately upon the birth of their daughter with a disability. They achieved more of it, over the years, much as anyone acquires skills through a developmental process. "Once upon a time, a decade ago," *About* took action, and continued to take it "over the years."

Empowerment exists when the family *feels* they can have some control over their lives. *About* said, "We're seeking empowerment," indicating they feel they can have some control over their lives.

Empowerment also consists of the fact that the family does achieve some mastery over some aspect of their lives. *About* took a path that helped themselves and "even you."

The Responsive Context

But a family is just one of the actors in the empowerment drama. In every family 's life, there are many others. Even the family that feels the most empowered and takes the firmest action will find that it makes no difference unless others respond positively. Empowerment requires a *responsive context*. Thus, *About* said to providers, "Work with us! Please honor our choice!" Obviously, the providers listened to them "*About* changed themselves and systems, too." By changing systems, *About* "chose path that has helped even you." In short, they created a responsive context for themselves and for others as well.

Thus, empowerment is a purposeful developmental process aimed at helping a family gain mastery over its life and environments, consisting of motivation, skills, and resources, and causing changes in the family and in the systems with which it relates.

Origins of Empowerment

We still have more to learn. But we have to leave the poem's text. Like most analysts, we need to examine the context within which the poet wrote. Let's start by examining empowerment's origins.

Empowerment originates in political theory about democratic government. Government of, by, and for the people is the familiar phrase – one that asserts that the people have power over their governments.

Empowerment also derives from social programs of the early 1960s. These programs lived by the phrase "Power to the People" and embodied it in model cities and community action programs. Nowadays, politics of the right and the left both pay tribute to empowerment but advocate different strategies.

Empowerment finally reflects psychologists' efforts to help people be healthier and to cause their communities and public policy to respond more to their needs.

Thus, empowerment derives from political theory, social programs, and policy reform proposals and from several disciplines. Accordingly, it is best understood when each of these perspectives is taken into account.

Criticisms of Empowerment

Good poetry deals artfully with important subjects. Certainly no one (especially not I) would applaud this poem's artfulness. Let's move beyond form and style, however, and consider this potential criticism: yes, the poem addresses a significant issue but it does so in wrong-headed ways. Can that be said of this poem? Perhaps so, on two grounds, but both are without merit.

Families Already Have Power

Some people object to the very term and concept of empowerment. They say that families already have "power" and that no policy or professional (in the disability field) can "give" them what they already have. We believe this view does not represent an accurate understanding of empowerment.

The fact of the matter is that by far the greatest number of families do have and feel that they have inherent power, motivation, skill, and potential for impact on systems that serve them and their children with disabilities. The poem acknowledges this fact by featuring the A*bout* family. At the same time, some the case with the *Doubt* family. Empowerment does not necessarily mean that someone has to give power to a family. That could be the case. It equally can be the case that a family, such as *Doubt*, takes the initiative to become more empowered.

It is also true that most families have to share power with professionals. Sharing can be useful, or not, for the families. In sharing their lives and power, *About* changed themselves "and systems, too." The poem's message is clear: public policy should indeed foster shared decision making between family and professional, and it should encourage family participation in policy and research activities.

Empowerment Research is Misguided

Some also say that research on empowerment is misguided. Research on shared decision making and family/professional collaboration. they argue, legitimizes power in professionals, whereas power should lie only or at least primarily in families. They also contend that empowerment research assumes families are dysfunctional and can best be understood only from a "deficit" perspective.

Again, we disagree. Research on the process, components, and impact of family empowerment does not assume that the families are dysfunctional or deficit based. Rather it assumes that families are indeed inherently strong (like Ab*out*). Their empowerment behavior (motivation, skills, resources) is worthy of study. Only with study will we know how to increase empowering behavior in others and how empowering behavior makes the families' worlds more responsive. These worlds include the formal service systems and the informal or other mediating structures, such as religious, community, or other groups. Thus research about families in context is desirable; and research about systems change is, too.

Indeed, too much research already has examined families' "deficits/pathology/brokenness." True, we need to understand what causes them stress and how to help them cope. But even more, we need to know why A*bout* approaches life with a sense of purpose and strength ("But some skills we have, and others we'll find... We're feeling empowerment.") This is so because A*bout*'s empowerment affects not just professionals but also "neighbors and friends, and clergymen too." *About* affected their informal or mediating structures. And they did so in a most remarkable way: they evoked the generosity of others and thereby created a different kind of social security, a kind that no federal program can mandate.

Now, here at last is what we know and believe about empowerment, as exemplified by the poem:

- Empowerment' s origins are in political theory, social programs, and policy reform proposals, and its theoretical and research bases are in several disciplines.
- Empowerment is a process whereby families recognize their own power and use it to gain mastery over their environments.

- Accordingly, empowerment is best understood from a systems perspective, reflecting the fact that the family interacts with various environments.
- Empowerment exists when a family is able to combine its motivation with its own inherent or internal skills and with external resources and, by bringing the combination of motivation, skills, and resources to bear on their environment, cause that environment to change.

Thus, empowerment warrants research of individuals, families, professionals, and other individuals in certain contexts. In the disability field, the usual context is the formal service provider system. Because families do not relate to only that context, empowerment research should also focus on families' interactions with informal or mediating structures.

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Appendix C

Empowerment: Dependence vs. Independence

By Frank G. Bowe, Ph.D.
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Empowering Americans with disabilities to take charge of their own lives never has been more important – or more possible. Yet in many ways, it's never been more difficult.

The events of the past few years have led many to believe that the job already is done, at least in major part. They're wrong.

The fact is that, with respect to the bulk of the population of Americans with disabilities, we're standing still. The Americans with Disabilities Act (ADA) will help. How much it helps will depend not only on how it is implemented and enforced but also on how energetically Americans with disabilities adopt the lifestyles it makes possible. For millions, this means radically altering how they live their lives.

That's ironic in light of the efforts we've made to empower people with disabilities in this country. In this paper, I will raise the question: "What steps can we take now to empower the population?" I'll begin by outlining what we say we're doing, then track what we're actually doing. The evidence seems to suggest that we've empowered people with disabilities in legislation only; they've not yet incorporated into their thinking the life altering choices new laws have given them. Until they do, they won't consider themselves to be empowered.

Dependence versus Independence

The empowerment movement, broadly speaking, is that thrust in which we as a nation say to individuals with disabilities: "You can live a life of achievement, independence, and self sufficiency. To assist you in that effort, we as a society will do our part. We'll enforce federal laws protecting you from unfair discrimination in education, employment, and everyday life. We'll also invest billions of dollars to provide you with the skills you need to support yourself in gainful employment. And we'll remove community barriers that stand in your way."

It's a beautiful sentiment, particularly to a civil rights activist like myself. I've spent twenty years helping to fashion this "independence message." I believe in it and I think most Americans with disabilities agree with me. The evidence, though, is that we still have much more to do for this message to take hold.

The counter movement, which I sometimes call the "dependence" alternative (Bowe, 1980), dates from the 1954 amendments to the Social Security Act creating Social Security Disability Insurance (SSDI) and the 1974 amendments creating Supplemental Security Income (SSI). These programs, together with Medicare (for SSDI recipients) and Medicaid (for SSI recipients), sent a very different message to Americans with disabilities. They say: "Society has an obligation to support you as people who should not be obligated to support yourselves. we'll provide a safety net as long as you need one." Although this message has been modified by 1980 and 1986 amendments to the Social Security Act so as to remove some "work disincentives," the core message remains the same today. That's particularly true because many SSI recipients don't believe the Social Security Administration when it says that those changes make it safe for SSI recipients to work to support themselves.

The evidence is that the "dependence" message has taken hold, and remains dominant, despite all efforts to wean dependent individuals with disabilities from it. The 1986 Louis Harris and Associates poll (ICD/Harris, 1986) found that two thirds of adults with disabilities who were on entitlement rolls would rather be working. That's what they said. So one would expect that at least some would move from aid rolls to pay rolls.

It doesn't seem to be happening. The first data from the 1990 Census of Population and housing show us that as few adults with disabilities were working to support themselves in the 1990 as was the case in 1980 (Bowe, 1986a). The 1990 census found that 60.6 percent of "working-age" (16–64 year-old) adults with work disabilities were not even participating in the work force. These 7,782,459 adults neither worked nor were actively seeking employment when the census was taken in April, 1990 (Bureau of the Census, 1992).

That only 39.3 percent of adults with work disabilities were in the labor force in 1990 – after the 18-million strong growth in jobs in the 1980s – is bad enough. That so few worked despite some $20 billion in federal, state, and local spending each year on special education, more than $2 billion in federal and state outlays on rehabilitation annually, and untold sums in private and public investments to remove architectural, transportation, housing, and communication barriers is, if anything, worse.

The recent numbers we have tell us that a majority of working-age adults with disabilities neither work nor actively seek employment. Today, putting it baldly, most adults with disabilities do not work. That's hardly the result we would expect from the concerted efforts we made to empower the population.

There's another concern. The costs of maintaining large numbers of Americans with disabilities on the entitlement rolls has mushroomed in recent years. Today, the SSA counts more than eight million persons with disabilities on its SSI and SSDI rolls. Entitlement programs such as SSI, SSDI, Medicaid, Medicare, and veterans benefits total more than $290 billion on the federal level alone. Whether we as a nation can continue to pay such costs is an open question.

Whether we should, given that these programs disempower millions of Americans with disabilities, is equally questionable. I have great difficulty believing that as many as eight million people with disabilities truly cannot work, given modern adaptive aids and accessible personal computers.

These programs are controversial among people with disabilities. Some argue that SSI and Medicaid are, in effect, welfare "handouts" that people can get just by being disabled, without having to work for them. Individuals with disabilities who worked hard to get an education, and then worked even harder to get and keep a good job, sometimes resent the fact that others with the same kinds of disabilities do not have to work to buy food and clothing, pay the rent, and receive medical care. Seen in this light, SSI and Medicare can rob people with disabilities of the incentives needed to become independent, self-supporting citizens.

Other advocates are angry because SSI and Medicare have many outdated rules that make it difficult to get off these aid rolls and onto payrolls. Some youth and adults with disabilities who benefit from SSI are still concerned they may lose eligibility if they engage in "substantial gainful activity," which usually means earning more than $500 a month. To place that figure in context, consider that it means making the minimum wage at a 35-hour-a-week job. A 1986 amendment – section 1619 – to the Social Security Act allows some individuals to earn much more and yet keep Medicaid coverage. This program was designed to encourage SSI recipients to accept jobs paying more than the previously allowed amount. In fact, relatively few SSI recipients have left the Social Security rolls for payrolls under the section 1619 program.

These SSI and Medicaid rules disempower millions of Americans with disabilities. For some, SSI and Medic aid are necessary; these people, most of whom are severely disabled, have no real choice. Others can be helped, however. The foundation for empowering these people is largely in place.

Empowerment Legislation

We mark the beginnings of the modern disability empowerment movement with the Rehabilitation Act of 1973. PL 93-112 required development of an "Individualized Written Rehabilitation Plan" (IWRP) by each client and his or her counselor. Two years later, in the Education for All Handicapped Children Act of 1975, Congress mandated the preparation for each child with a disability of an "Individualized Educational Program" (IEP). This document was to be prepared by school officials with the approval of the child's parents (and, where appropriate, of the child as well).

In addition, parents were granted remarkable rights to access all school records about their child, to appeal decisions with which they disagreed, and to materials in their native language. Later versions of the law, now called the Individuals with Disabilities Education Act (IDEA), added an Individualized Family Services Plan (IFSP) for infants, toddlers, and their families, and an Individualized Transition Plan (ITP) for adolescents age sixteen or over. Taken together, these written plans provide meaningful opportunities for people with disabilities and their families to take charge of their lives. Ideally, IEPs, ITPs, and IWRPs are developed in concert, permitting individuals with disabilities to map out a coordinated strategy for reaching personal goals.

Other legislation has reached deep into the private sector to empower individuals with disabilities seeking access to community life. The Fair Housing Amendments Act of 1988 permits persons with disabilities to make access modifications in apartments and condominiums, forbidding landlords to bar such alterations. In addition, real estate agents, brokers, and landlords are required to practice nondiscrimination in all aspects of their work with prospective tenants and homeowners. The law further requires that all new apartment, cooperative, or condominium buildings with four or more units be constructed to be both accessible (wide doors, ramps, etc.) and adaptable (controls, cabinets, etc., that are readily lowered or raised).

The landmark Americans with Disabilities Act of 1990 granted to individuals with disabilities the most far reaching civil rights accorded persons with disabilities by any nation in the world. Reaching deep into the private sector, the ADA requires virtually every employer with fifteen or more workers to practice nondiscrimination in employment and to make reasonable accommodations as needed so that individuals with disabilities may perform jobs for which they are qualified. It ended twenty years of acerbic national debate about access to transportation by mandating access to mass transit, commuter rail, and intercity buses.

The Act requires millions of businesses serving the public, such as stores, doctor's offices, entertainment centers, sporting complexes, and laundry establishments to make their services available on an "equal enjoyment" basis to customers with disabilities. The ADA also extended to persons using Text Telephones (also called TDDs) full and equal access to the nation's public switched telephone network, including all telephones connected to any of the country's 1,600 local exchange companies (LECs) and all of its long-distance carriers.

In addition, the Act granted to individuals with disabilities the right to charge violations of their civil rights in private-sector employment, in state and local governments, in "places of public accommodation" such as shopping malls and movie theaters, and in telecommunications.

These laws provide a framework for empowering people with disabilities. For Capitol Hill, the greatest challenge now is to create a single, coherent national policy on disability. To date, the two streams of legislation have proceeded almost unaffected one by the other. The 1974 SSI law and its 1980 and 1986 amendments, on the one hand, established and perpetuated the "dependency message." A separate stream of laws beginning with the 1973 Rehabilitation Act and the 1975 education law, and continuing through the 1990 ADA, created and expanded the "independence message." The task for the U.S. Congress now is to articulate to the American population of people with disabilities a single message. That will take time. Meanwhile, there is much we can do.

Vehicles of Empowerment

The Americans with Disabilities Act charged federal agencies, notably the Department of Justice, the Equal Employment Opportunity Commission, and the Department of Education, with providing technical assistance and information about the ADA. Notable among the efforts undertaken to carry out these mandates are a $1 million contract from EEOC to the Disability Rights and Education Defense Fund (DREDF) to train disabled activists on helping to implement the ADA. The Department of Education has funded a network of ten ADA technical assistance centers, as well as several materials development centers. The Department of Justice awarded grants for more than a dozen projects aimed at accelerating compliance by such covered entities as restaurants, hotels, and labor unions.

Still, in view of the census information, we need something more if we are to fully empower tens of millions of Americans with disabilities. I like the idea of looking to "independent living centers" (ILCs). The Rehabilitation Act, as amended in 1978, created what is now a 466-strong network of local centers for independent living. Most congressional districts have at least one such center. The centers are governed and staffed largely by individuals with disabilities. These advocates are active at the local level, especially in peer counseling. Their focus on the community and their tradition of peer support position them ideally as vehicles of empowerment. I would like to see them focus their energies on informing community residents of their rights.

An excellent local project for an ILC would be to encourage each area resident with a disability to speak up at each store, restaurant, hotel, and other covered entity he or she visits in the normal course of events. It may not take much more than a comment – "I'd like to shop here, and I could, if you'd do what the ADA calls for." Multiplied over millions of peopie saying this in tens of millions of businesses, such small steps would do more to stimulate implementation of the Act than almost anything I can think of.

The women's movement accelerated in the late 1960s and early 1970s because of exactly such actions. Millions of women became aware of entrenched paternalistic attitudes and made the small, individual decisions to assert themselves as equals. The women's movement asked each woman to act on her own, at home and at work. That was something virtually every woman in America could do. Centers for independent living can ask Americans with disabilities in the 1990s to take similar small, local steps. Importantly, such actions permit these individuals with disabilities to begin to take responsibility for their own lives. As they learn what the laws require, and ask that local companies do those things, they'll empower themselves.

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Appendix D
Advocacy: Noun, Verb, Adjective, or Profanity?

by Linda Cress Bonney and Sandy Moore

Depending on your perspective and your personal experiences, advocacy can be exciting, challenging, frustrating, frightening, or a relief. Advocacy is often misunderstood. Yet, all of us at one time or another have found ourselves acting as an advocate for our children, our students, our friends, or ourselves.

For the purposes of this article, *advocacy* is defined as information, advice, and representation provided to individuals and their families to assist them in acquiring appropriate services for a person with a disability. An *advocate* is a person trained to provide support, advice, and legal representation to persons with disabilities.

Law, regulation, and policy set out a process and procedural safeguards within each service system for persons with disabilities. This is true of social services, education, and the health care systems. The process of accessing any service includes at minimum, application, eligibility, assessment, service plan, service delivery, and delineation of financial responsibilities. When this process is working well, there is no need for an advocate. When there is conflict or disagreement in accessing or providing services, then an advocate might be called. The primary purpose of an advocate's involvement is to resolve conflict. The advocate's role is to serve as a "guardian of the process" to ensure that the required steps are taken to identify and meet the needs of the people that each system is mandated to serve.

Families are often referred to an advocate by other families or professionals who recognize that the process has been derailed and that an outside party will be needed to get it back on track. Persons often request the assistance of an advocate as a last resort. Many have been threatened with discontinuance or reduction of services. Some of these people will have attended many meetings, without results, while others were unaware of their right to convene a meeting at all. Some will have identified and repeated the problem as they've been passed from one agency to the next, while others may not have found someone willing to listen or help.

At this point, families and professionals are often feeling angry and frustrated. Family members may be reluctant to involve an advocate, not wanting to be seen as troublemakers and being fearful of possible retribution to their family member with a disability. Professionals may be feeling defensive. People with disabilities, their families, and friends need to realize that they may be in that painful position of choosing between "not rocking the boat" and getting what is needed for the person with a disability.

It is not the role of an advocate to dictate the outcome, but rather to direct the process to reach the desired outcome, which is implementation of services designed to meet the unique needs of the person and family. The first step for the advocate is to gather the information necessary to identify the problem and determine where and how the process got derailed. The advocate will often be seen as a persistent person who asks and re-asks many questions regarding the details of what has taken place, the players involved, and the roles and power of these players. The advocate will need to look carefully at all of the relevant assessments and information to ensure that there is documentation supporting the professional recommendations and decisions that are being made. This is where the advocate's knowledge of the laws and regulations is critical in order to determine the appropriate strategies to employ.

The advocate's job is not to ensure that all participants are comfortable or happy, but to ensure that the person with a disability gets the needed services. Yet, a successful advocate will be an experienced problem solver, and will work to move the team towards resolution in a focused, positive manner. A skillful advocate will always be aware that their presence is temporary, while the person with a disability and family will continue working with many of these service providers on a long-term basis.

While working through specific issues, the advocate has a responsibility to help build others' confidence and skills so that all the people involved will be better equipped to deal with problems in the future. In addition, the advocate attempts to build the supports necessary for the individual and family to continue to informally advocate for them selves, and for them to know and follow the processes that ensure provision of services throughout life.

There are several things that persons with disabilities and family members can do to more effectively use advocacy. First, they can learn as much as possible about the program(s) they are working with, and, before problems arise, ask for written information on their rights and the appeal process for each program. They can also identify which professionals are responsible for assisting with which types of problems. Secondly, as problems arise, it's important that individuals and families identify what they want and/or don't want in services before contacting an advocate. And finally, it's better to request assistance before doom appears inevitable. We have yet to meet an advocate with wings, and there is seldom a magic answer that offers a "quick fix" to long-standing problems.

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Appendix E
Confessions of a Paraprofessional

By Mary F. Hayden

I am a social worker by trade. I entered the profession with the belief that social change could occur through the various methods of community organization, such as social protest, advocacy, lobbying, whistle blowing, and self-help action groups. Through the years I have participated in sit-ins, advocated for individuals and classes of people, and led self-help groups. Because of these experiences, I view myself as a "good guy".

When asked to plan and coordinate an all-day working conference on the issue of self-advocacy, I was excited to be given the opportunity to educate other professionals and to show them how to mend their ways. However, I found this holy campaign to be my own personal awakening. I was surrounded by many teachers. Through their actions and accounts of their personal experiences, they taught me that professional good intentions may hinder people with disabilities from speaking out for themselves. I found that even a "good guy" has room for improvement.

Prior to meeting the other participants at the conference, the word "client" would flash before me during conversations with them. I would become angry and tell myself that the correct term was "consumer". After I met with everyone at the conference, I was gently told that the "correct term" was *people with disabilities*. Through working closely with everyone, the labels quickly went by the wayside.

Lesson 1: ***Don't label people.***
Get to know the person as an individual.

As a member of the helping professions, I found myself wanting to help. I wanted to do things for people. For example, some people had not stayed in a hotel and, as a result, they did not know how to check in and out, charge meals to the room, and tip bellhops. Initially, I took care of a number of these activities. I eventually learned to explain the hotel "system" to people and let people take care of themselves.

Lesson 2: ***People have the right to make choices in everyday life.***
Practice what you preach.

I wanted to protect people. This behavior ranged from telling someone that the area around the hotel wasn't safe to wanting to keep tabs on people. A series of events occurred that made me realize that my need to protect was a reflection of my focus on people's disabilities rather than their capabilities.

One afternoon several people decided to go to the Martin Luther King Center. I decided to use a rented car. One individual with a physical disability stayed behind. To my surprise, the person who "stayed behind" was at the Center waiting for us. I later found out that he preferred to travel independently rather than with a segregated group. Several other participants periodically left the group to either be by themselves or to meet new people.

Lesson 3: ***People have the right to discover, explore, and experience life.***

During the conference, the group worker within me became nervous; the group controlled the group process. Some people didn't talk while others monopolized the time. A few people were overbearing, some were more articulate than others, and some were more socially skilled. Initially, I believed someone (a professional) had to work the group dynamics to insure that the most relevant information was brought to light. Because of this, I listened to people who were brief, accommodating, articulate, socially skilled, and focused. However, the facilitator was able to get beyond the veneer. He listened and heard each person's message. Everyone made a contribution to the conference and it was duly noted.

Lesson 4: ***Don't judge a book by its cover.***
Listen to the person.

As these and other events occurred, I had a series of conversations with the other participants about when a behavior is a reflection of caring and support or when it's a reflection of control and overprotectiveness. People shared their experiences through these conversations. They all provided examples of a professional's expertise and personal agenda overriding the wishes of a person with a disability. They gave accounts about how the social service system hinders personal growth. They shared moments where others judged their lifestyle. These conversations helped me to remember that I chose to work in the field to assist and support people with disabilities. They allowed me to re-affirm my belief that people should experience life to the fullest.

Lesson 5: ***The manner in which a person chooses to experience life may be inconsistent with our philosophy. These differences need to be simply acknowledged and appreciated. No value judgement is necessary.***

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Reprinted with permission from *Impact: Feature Issue on Self Advocacy,* Winter 1990/91, 3(4), published by the Institute on Community Integration (UAP), University of Minnesota, Minneapolis.

Appendix F

Out of My Old Life and Into My New One

By Michael J. Kennedy

I grew up in three New York institutions. In 1982, when I was twenty-one, I moved into a group living situation in the community called a supportive apartment. I lived with three other men with cerebral palsy, and we were supervised by staff whenever we were home. The supported apartment was much better than the institution, but in the six years I lived there I learned everything I could learn and was ready to be on my own. Also, the program was funded by Medicaid and had too many rules and regulations, like having to have goals and a service plan.

I knew what I wanted, but I needed help to get it. So I started talking to the director of the program about being on my own. I was listened to in one way, but not in another way because nothing was happening. What I had to do to get my point across was to threaten to move back into the institution near my family in the Adirondack Mountains area. The director got wind that I was actually going to do it, and the agency staff didn't want that. I know it would have been a mistake, and I didn't want to quit my job at the Center on Human Policy, but I felt my back was against the wall. That was the beginning of my getting my own home.

The agency told me about a new program they had just received funding for. It was called a Family Care program, but what it does is to match a person with roommates and the other supports he or she needs. One of the staff at the supported apartment, John, called me into the office one day and asked me if I would consider setting up a home with him and his roommate Gordy. I agreed, with the understanding that I didn't have to follow Medicaid rules or have a service plan. I wanted to make my own decisions. I made it very clear that when it was time to leave the program, I could just go, no strings or questions asked.

As time went on, the coordinator of the Family Care program met with John and me. I told her what I wanted in terms of supports and a home. Part of her job was to help us find a place. The exciting part is that we had a friend who used to work for the agency who was into buying real estate. One day I was kidding with her and said, "Why don't you buy a house that would be easily accessible and I would rent it from you?" About a week later she told me she had bought a house! At first I thought she was kidding, but then when she took me and John over to see it I knew she was serious. We called the coordinator on the phone.

John and I then started meeting with her on a regular basis. It was actually pretty easy to set up the supports I would need, like physical therapy and my orthopedic doctor, because I could just take what I had from the apartment and transfer them to my new house. The supports I didn't have at the apartment were just added on. For example, I had to arrange attendant care with one of the agencies in town. Medicaid would pay for all of this when I was on my own because I kept my Medicaid eligibility.

Always keep in mind that it may not be as easy for someone else as it was for me to set it up. The important thing you have to remember is that you should be involved in every aspect from start to finish. You, the individual, must have the supports built around you, and not be made to fit into a program that wasn't designed just for you. This is true regardless of how severe your disabilities are. It's very important that you have the say about how your wants and needs are dealt with.

If you work at an agency, I'd hope that you would go along with the individual on how he or she wants to live. You don't have to agree, but they have the right to live like anyone else.

I've lived on my own for the last two years. Through this period John and I have talked about moving down south. We both like the South for a number of reasons. One is that we both have family down there, and they have been asking us to move down there for quite a while. The most important reason is that both John and I felt we needed a change in our lives, we needed something new, and we needed to move on. So, we are moving to a town near Atlanta, Georgia. I am very excited about this move.

Michael Kennedy was formerly the Self-Advocacy Coordinator at the Center on Human Policy at Syracuse University, and is currently a consultant to the Center.

Reprinted from *Impact, 3* (4) Winter 1990/91, Research and Training Center on Community Living and the Institute on Community Integration at the University of Minnesota.

Appendix G
ADA Requirements Fact Sheet

Employment

- Employers may not discriminate against an individual with a disability in hiring or promotion if the person is otherwise qualified for the job.
- Employers can ask about one's ability to perform a job but cannot inquire if someone has a disability or subject a person to tests that tent to screen out people with disabilities.
- Employers will need to provide "reasonable accommodation" to individuals with disabilities. This includes steps such as job restructuring and modification of equipment.
- Employers do not need to provide accommodations that impose an "undue hardship" on business operations.

Who needs to comply:

- All employers with twenty-five or more employees must comply, effective July 26, 1992
- All employers with fifteen to twenty-four employees must comply, effective July 26, 1994.

Transportation

- New public transit buses ordered after August 26, 1990, must be accessible to individuals with disabilities.
- Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed route bus services, unless an undue burden would result.
- Existing rail systems must have one accessible car per train by July 26, 1995.
- New rail cars ordered after August 26, 1990, must be accessible.
- New bus and train stations must be accessible.
- Key stations in rapid, light, and commuter rail systems must be made accessible by July 26, 1993, with extensions up to twenty years for commuter rail and thirty years for rapid and light rail.
- All existing Amtrak stations must be accessible by July 26, 2010.

Public Accommodations

- Private entities such as restaurants, hotels, and retail stores may not discriminate against individuals with disabilities, effective January 26, 1992.
- Auxiliary aids and services must be provided to individuals

with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.

- Physical barriers in existing facilities must be removed, if removal is readily achievable. If not, alternate methods of providing services must be offered, if they are readily achievable.
- All new construction and alterations of facilities must be accessible.

State and Local Government

- State and local governments may not discriminate against qualified individuals with disabilities.
- All government facilities, services, and communications must be accessible consistent with the requirements of section 504 of the Rehabilitation Act of 1973.

Telecommunications

- Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices.

This document is available in the following accessible formats: braille, large print, audio tape, electronic file on computer disk, and electronic bulletin board. Call 202/514-6193.

For more information about the ADA, contact the U.S. Department of Justice, Civil Rights Division, P.O. Box 66118, Washington, DC 20035-6118, 202/514-0301 (voice), 202/514-0381 and 202/514-0383 (TDD).

Appendix H
The Kindness of Others

By Roberta L. Juarez

"I have always depended on the kindness of others..." is one of the most memorable lines from one of my favorite plays and until very recently it pretty well described the way people with disabilities interacted with society, or didn't interact. Well, *no more!*

Thanks to the newly-passed Americans with Disabilities Act (ADA), Americans with disabilities are now on a more even ground with their able-bodied brothers and sisters. Jobs, transportation, telecommunication, and public accommodations should soon be more fairly accessible.

As an adult with cerebral palsy who spent far too much effort and money on a college education to be told she wouldn't be considered for a professional position because her "co-workers would feel uncomfortable around her", I am thrilled to know it will soon be illegal to consider my disabilities rather than my abilities. Even if I need something changed to make my job easier to perform, Uncle Sam says it's okay as long as it's reasonable.

When this dream job affords me that well-deserved three-week vacation, I should be able to take a few things for granted: I'll be able to travel to my destination using the transportation system of my choice; I'll be able to ask for an accessible hotel room and actually expect to get one; and if I want to call a friend who has a speech or hearing impairment just to remind her that she's at work and I'm not – an appropriate telecommunication system will be available.

If I were still in high school, the ADA would still prove important. Even though it does not touch directly on education, the ADA will strongly impact "education" outside of the classroom. No longer will an adolescent be denied a trip to the movies with his friends because the theater is inaccessible, or the bus doesn't have a lift. No longer will he be unable to call a classmate to commiserate over the unfairness of today's pop quiz because his friend doesn't have as TDD. He can use a free, confidential telephone interpreter service. Although these activities may seem unimportant, even trivial, they are not. Some of the most important lessons are learned outside of the classroom.

More obvious is the fact that his education will really be worth something because when he's ready, if he's qualified, he will get the job.

One other thing about the ADA – it eliminates the excuses for parents and individuals with disabilities not to be assertive when it comes to accessing the services they need for their children or themselves. The days of relying on the kindness or paternalism of others are gone. People with disabilities have just become first-class citizens. It's up to all of us to make the most of it.

Roberta L. Juarez, M.S., R.D., works for the Metropolitan Center for Independent Living in Minneapolis.

Appendix I
Section 504 Fact Sheet

What is it?

Section 504 is a section of the Rehabilitation Act of 1973 which protects the rights of persons with disabilities. It prohibits agencies or organization which receive federal funds from discriminating against otherwise qualified individuals solely on the basis of disability.

What is a disability under 504?

An individual is determined to have a disability if he or she:

1 Has a physical or mental impairment which substantially limits one or more major life activities (walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, performing manual tasks);

2 Has a record of such impairment; *or*

3 Is regarded as having such an impairment.

This can mean that a school-age child who has an attention deficit disorder and does not qualify for special education services may still be entitled to accommodation in regular education under Section 504.

What are "reasonable accommodations" under 504?

Accommodations must achieve meaningful equal opportunity, must consider the functional limitations of the person and alternative methods of performance. Some examples could be the following: modified testing, preferential seating, taped textbooks, readers, tailoring homework assignments, etc.

Are evaluations and IEP required?

A district must evaluate "any person who, because of handicap, needs or is believed to need special education or related services". Evaluation is also required prior to a significant change in placement.

A written plan describing placement and services must be developed. A formal IEP is not required, but decisions will be made by a group of persons. Placement decisions must be based on information from varied sources and must be documented. All information must be considered. Decisions must be made by a group of persons who are knowledgeable about the child, the meaning of the data, and placement options.

What are the responsibilities of schools?

Schools must provide assurance of non-discrimination, designate an employee to ensure compliance, provide grievance procedures, identify and locate all qualified children with disabilities who are receiving public education, provide notice of district's 504 responsibilities and procedural safeguards. The procedural safeguards are as follows:

1 The right to written notice
2 The right to review records
3 Theright to an impartial hearing

What if there appears to be a violation?

The Office of Civil Rights investigates Section 504 complaints. Minnesota is in Region Five, 300 Wacker Drive, Chicago, Illinois 60606; Telephone 312/353-2520.

Appendix J
Who Can Teach Change Better?

By Beatrice Roth

In the early days when I was first asked to be a chapter advisor with Speaking for Ourselves, finding guidance material on my role was almost impossible. I was told, "Your members and your heart will teach you." How true, and the lessons began immediately.

As a guest observing my third monthly meeting of the group, the President once again welcomed me and expressed appreciation at my interest. Before fully understanding what was happening, I found that I had been nominated and voted in as a chapter advisor. I know now that this was the start of a whole new way of thinking, a way of reacting – or better still, *not* reacting.

To assist others, to step in and help, had been instilled in me since childhood. But, to "assist" often meant to take over and do it myself. I learned that an advisor does not take over. An advisor supports and is a friend. The leadership role belongs to members.

For example, my natural tendency is to push my own opinion of who's best suited for chapter officers, which are elected on a yearly basis. But, time has taught that an advisor listens first to what members have to say. Their fingers are on the pulse of what is best for them. Those with top leadership abilities have already taken the foreground over the previous year and members have an instinctive knowledge of who can best represent the group.

When an individual speaks out on his or her own behalf, the message is from deep within. Who better knows what needs to be changed? Who can better describe the pain experienced and the frustration of unanswered needs? Who more has felt the effects of people ignoring their simple entreaties for everyday wants and desires? Individuals need only to be encouraged to step forward and speak out. Expressing reassuring faith in our members as individuals, exploring options, affirming abilities, is a vitally important role of an advisor. It can't be faked. It starts with listening as a true friend, prompting someone who has been devalued by society to expose their wounds, to trust you, to believe in him- or herself. It's not easy for people that have been repressed and relegated to the background to freely speak out about what's hidden inside. But it's important for others to hear and understand the effect of their often unintended actions that hurt. The story needs to be told. Again, the advisor's part is that of a student learning from a teacher, our members, who can best instruct from self knowledge. Their insight gleaned through life's heartaches is the best teaching tool in bringing about change. An encompassing circle of experience, learning, educating, and support is shared by members and advisors alike.

One way the story is told is as members speak out on issues dear to them during the annual Speaking for Ourselves Conference. This event, planned, executed and presented from start to finish by Speaking for Ourselves members, is directed toward educating the world at large, parents, professionals, and staff about issues such as real jobs, community integration, and awareness of the many capabilities individuals with developmental disabilities offer to today's society. An event of this size is only successfully accomplished through the dedication, systematic planning, and teamwork of members from all chapters. Throughout this, the advisor is a strengthening backer, an affirming friend, providing transportation, paperwork and support backup. But, most important is the vital role of encouragement, being there when needed to prompt someone to take that scary next step.

My friends at Speaking for Ourselves inspire me to greater heights in life. It's why being an advisor is one of the greatest enjoyments of my life, just rubbing elbows with so many wonderfully courageous and determined people. It's a two-way street where each learns and teaches, where all of us together in Speaking for Ourselves educate those in the world around us in the ways to a better life not just for individuals with disabilities, but for us all.

Beatrice Roth is Advisor for the Montgomery County Chapter of Speaking for Ourselves in Montgomery County, Pennsylvania, 215/549-0550.

Appendix K

NICHCY Newsletter on Self-Determination

NICHCY

TRANSITION SUMMARY

National Information Center for Children and Youth with Handicaps

NUMBER 5 1988

SELF-DETERMINATION

The purpose of this issue of *Transition Summary* is to acquaint readers with the issues of independence and self-sufficiency -- sometimes called self-determination or self-advocacy -- that young adults with disabilities face as they look toward the future. In this issue, we also offer parents guidelines, insight, and practical advice on helping their children with disabilities cultivate some of the skills they will need to function more independently as adults.

People with disabilities have diverse needs and abilities. Someone with a physical disability may have different needs from someone with mental retardation; likewise, someone with learning disabilities may have needs that differ greatly from someone with an emotional disturbance. In spite of this diversity, however, most people with disabilities have this in common: they can express their own viewpoints, and can make informed decisions about matters that affect every aspect of their lives.

This *Transition Summary* does not attempt to present the diverse needs of people in different disability groups or the needs specific to any particular disability group. Instead, the focus is on the need for young people with disabilities to take charge of their own lives and to speak for themselves in an effort to overcome discrimination, segregation, and unequal opportunities based on disability. Also discussed are the rights and needs of these individuals to live with dignity and respect; to have the same opportunities to fail and to succeed as people without disabilities; and to no longer be seen as individuals perpetually dependent on welfare and charity.

In most families, an adolescent's transition to adulthood is a stressful period. For families with children who have disabilities, the transition may be even more disruptive. The forms that the stresses may take and the ability to react to those stresses will vary from family to family, depending on the number of family members, the family's geographical location, their social and financial resources, and their personal values and beliefs (Brotherson et al., 1986).

For parents, the period of transition means learning how to gradually let go, becoming less protective, and fostering in their child a sense of self-assurance, self-reliance, and responsibility. For many young adults, transition means leaving school and/or home, and undergoing personal change as well as changes in their relationship with their [illegible]. It means having more independence and more responsibility.

Recently, people with disabilities have begun to consider themselves a minority group denied basic rights, such as attending public schools, becoming employed, marrying, and bearing children (Funk, 1987). Indeed, only in the past two decades have many rights and freedoms -- taken for granted by nondisabled persons -- been made available to people with disabilities. According to a recently conducted nationwide survey of 1,000 disabled people, "there are clear signs of an emerging group consciousness among disabled persons" (*The ICD Survey of Disabled Americans*, 1986).

Today, the focus of civil rights legislation for individuals with disabilities is "to assist individual disabled people to achieve a normal life experience as a citizen, not to create a nearly normal person as has been the focus of human service providers" (Funk, 1987). Along with the need to be recognized as people with their own rights, there is a call to reconsider the ways in which society thinks about and treats disability and the disabled. According to Thomas (1982), "One of the failures of our society is...its [inability] to comprehend the normality of handicap. It is the overwhelming insistence that we perceive and encourage 'the disabled' to perceive themselves as deviant that is the root of the problem." Thomas further observes that cultural attitudes toward those with disabilities have progressed through three stages: in the first, the person with a disability was considered helpless; in the second phase, skilled professionals became involved in "helping" those with disabilities; and in the third stage, persons with disabilities exhibit determination and question their roles as passive recipients of help (Thomas, 1982).

According to Gartner and Joe (1987), what is needed in education and other human service fields is "a recognition of the range of humankind, the awareness that all individuals possess both strengths and limitations, in varying mixtures and to different degrees." This requires that we avoid the use of terms and language that either deny the fact of the disability or that dispel reality. "Being disabled is not a 'challenge'... [the disabled] ... voluntarily undertake. Nor is it that we are merely 'differently abled.' We are disabled; there are just some things we can't do, at least not as quickly or as easily as other people" (Browne et al., cited in Gartner and Joe, 1987).

This issue of Transition Summary *contains articles about self-determination and becoming a good self-advocate. Ironically, much that has been written about these subjects has come from professionals rather than from people with disabilities. Each of the articles in this publication, however, reflect the experience of someone who has grown up with a disability.*

Ω

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THE MANY FACETS OF SELF-DETERMINATION

by Michael J. Ward

In the article that follows, the author describes his concept of self-determination and discusses parents' roles in encouraging their children with disabilities to trust and respect themselves, to gain self-assurance, and to become as independent as possible.

Michael Ward is the Chief of the Secondary Education and Transition Services Branch at the Office of Special Education Programs, the U. S. Department of Education. Before holding this position, he was a rehabilitation counselor for adults with developmental disabilities in Brooklyn, New York.

He grew up in Brooklyn, where he attended public schools. Recently, he completed a Ph. D. in Special Education at the University of Maryland.

Dr. Ward has cerebral palsy and uses a wheelchair.

What is Self-Determination?

Self-determination has been defined in a variety of ways. The *American Heritage Dictionary* (1976), defines it as "the determination of one's own fate or course of action without compulsion: free will." Another source defines it as "decision according to one's own mind and will" (*Webster's New World Dictionary*, 1972). A common element in both definitions is the importance of people taking control, without undue external influence, over what affects their lives.

Self-determination refers both to the attitudes which lead people to define goals for themselves and to their ability to take the initiative to achieve those goals. Acquiring the personal characteristics which lead to self-determination is a developmental process that begins in early childhood and continues throughout adult life. While it is important for all people to acquire these traits, it is a critical -- and often more difficult -- goal for people with disabilities. They must first shatter the pervasive stereotypes which imply that they cannot, or perhaps should not, practice self-determination.

The traits underlying self-determination include self-actualization, assertiveness, creativity, pride, and self-advocacy. The terms "self-actualization" and "assertiveness," borrowed from modern psychology, are important in the development and personal growth of all individuals. Self-actualization refers to realizing your potential and living your life accordingly. Assertiveness is being able to express your needs clearly and directly and to act and speak out with self-confidence (Des Jardins, 1986). Creativity is the ability to be innovative; to move beyond stereotyped images and expectations. Pride in yourself and your abilities is a trait that translates into feeling good about the contributions you can make to society. Self-advocacy, an essential component of self-determination, refers to the ablility to act on your own behalf. This concept is an outgrowth of the grass-roots disability movement of the last 20 years, a movement which has given disabled people the right and power to take necessary, but often unpopular, actions to ensure that their basic civil rights and social and economic needs are addressed. For people with disabilities, self-advocacy is "running risks, challenging rules, and acquiring resources" (Varela, 1986). It also involves "knowing your basic human rights; standing up for your rights; taking responsibility for your life; and asking for help because you want it or need it" (McGill, 1978).

Achieving self-determination, to borrow a concept from Gestalt psychology, is definitely "more than the sum of its parts." It requires not only that people with disabilities develop inner resources, but that society support and respond to these people. Self-determination is a lifelong interplay between the individual and society, in which the individual accepts risk-taking as a fact of life and in which society, in turn, bases an individual's worth on ability, not disability.

Persons with disabilities who want to achieve self-determination need to learn how to trust and respect themselves. They also need to learn to identify their rights and needs and to find the most appropriate ways of communicating these to others. But most importantly, people with disabilities must acquire a sense of political purpose and an understanding of their rights, responsibilities, and the democratic process (Williams and Shoultz, 1984).

Historical Perspective of the Disability Rights Movement

For centuries, society as a whole treated people with disabilities as objects of pity and fear. They were viewed as incapable of participating in or contributing to society. Prior to the 20th century, societal attitudes reflected the view that persons with disabilities were "unhealthy, defective, and deviant," requiring "special institutions, services, care, and attention in order to survive" (Funk, 1987). The national policy that grew out of such attitudes emphasized the reliance of people with disabilities on welfare and charitable organizations.

Even today, many people assume that children with disabilities are segregated from non-disabled peers because they cannot learn or because they need special help or protection. Similarly, for many, the absence of people with disabilities in the workforce is obvious proof that such people cannot work. Little thought is given to the idea that people with disabilities, in fact, are discriminated against (Funk, 1987).

Despite efforts through public policy in the 1950's and early 1960's to integrate persons with disabilities into community programs, societal attitudes had an isolating effect on persons with disabilities, forcing them to identify with and participate in groups of their own kind. Goffman (1963) wrote in the classic work in disabilities literature, *Stigma: Notes on the Management of Spoiled Identity*, that the relationship of such people to informal and formal community organizations made up of their own kind is crucial to the self-concepts of group members. However, his book was written long before it was recognized that persons with disabilities could use these organizations to improve their social status, and thus reduce the stigmatizing effects of segregation and isolation. The social and political climate of the civil rights re-

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form movement of the 1960's greatly influenced the disability rights movement. The role of people with disabilities shifted from passive dependence to active involvement. Rather than being recipients of philanthropy, they were becoming active participants in a far-reaching civil rights movement that challenged the stigmas associated with other minority groups, as well, such as ethnic minorities, women, gays, and the elderly. This shift in attitude raised the consciousness of these groups to the point where "the minority group is no longer one for whom pleas, reforms and changes are made by others, but where they themselves [those in the movement] are instrumental in provoking change" (Thomas, 1982). People with disabilities began to understand that, among their rights, they had freedom of choice and freedom to belong to and take part in society (Funk, 1987).

Along with the civil rights movement of the 1960's, local independent living centers emerged across the country. Weiner (1986) defines an independent living center as "a community-based program that has substantial disabled citizens' involvement and leadership and provides directly, or coordinates indirectly through referral, those services necessary to assist disabled individuals to increase self-determination and to minimize dependence." One of the first such centers was the Center for Independent Living, established in 1964 at the University of California at Berkeley. Its impact was far-reaching. Not only did it provide a wide range of services to the community it served, it was created by people with disabilities to meet their needs as they saw them. Thus, it became the symbol of all that those with disabilities could achieve, given the chance, and gave momentum and credibility to the independent living movement and the concept of self-determination.

The acquiring of self-determination is not limited to persons with physical disabilities. People First and United Together are two disability consumer organizations made up of people with mental retardation and their aides.[1] These organizations offer evidence that although it is often difficult for people with mental retardation to express their needs clearly, they can learn to manage an advocacy organization (with help), and can make decisions that affect their lives. Self-advocacy cannot be reserved for the "elite" among individuals with disabilities. People with mental handicaps who cannot communicate well can and should be encouraged to contribute in self-advocacy groups. With time and help, they, too, can learn the skills they need to participate in issues that affect their lives.

> *. . . it is difficult for adolescents to be independent psychologically and emotionally from their parents when they are dependent on them for meeting their basic physical needs.*

Adolescence: The Critical Stage for Self-Determination

Manus and Manus (1983) discuss the theory that adolescence is a phase in which young adults, both with and without disabilities, test their own knowledge, try out new roles, and rely on peer groups, rather than their families, for support. Generally, it is a phase in which young people challenge parental authority in order to assert independence and gain control over their lives as a necessary part of successfully moving into adulthood.

Many young people with disabilities have difficulty with this process of transition for several reasons. First, it is difficult for adolescents to be independent psychologically and emotionally from their parents when they are dependent on them for meeting their basic physical needs. Second, although adolescents without disabilities may encourage and reinforce the expression of differences, a disability may be a difference that they find unacceptable.

Some of the barriers that young adults with disabilities face are in fact found within the family structure. A major obstacle is not being given the right to fail. All adolescents must be allowed to "absorb the pain of failure, to react immediately to failure or to delay and react to failure later" (Manus and Manus, 1983). As children with disabilities become older, they should be given more responsibilities and the support they need to make their own decisions, even when parents feel that such decisions are not the best ones. Young people with disabilities need to learn that it is all right to fail and start over again. Failure can provide important opportunities for problem solving, decision making, and responding creatively to difficult situations. By being allowed to fail and to make mistakes, young people with disabilities can begin to develop an understanding of their abilities and limitations.

Parents and other adults can do much to encourage children with disabilities to exercise independence and self-determination. For example, children need to be included in making decisions that affect the whole family, such as where the next family outing will be, what the next family car will be, or how family time will be spent. As early as possible, children should make decisions about basic issues that directly affect them -- what clothes they wear, for example, or how their bedroom furniture is arranged.

Parents should also encourage their children to perform household chores that are within their capabilities. It has been said that parents should never do anything for their children that their children can do for themselves. This is especially sound advice for parents reluctant to assign chores or responsibilities to their child with disabilities in the belief that he or she is already overwhelmed and should avoid anything that would make life more difficult. While doing chores may take longer for some people with disabilities, most are not in any overwhelming physical discomfort. Chances are that children who grow to feel overwhelmed by their disabilities may have been treated as "special" or "sick" by parents, siblings, teachers, friends, or relatives.

An important point for parents to remember is that children challenge their parents in a sincere and necessary attempt to become independent adults. For young people with disabilities, this conflict may be more difficult or prolonged, but it is just as necessary as it is for all young adults.

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[1] The aides in these organizations are non-handicapped helpers who provide support and assistance with the development of ideas, but who do not function as leaders in the organization (Williams and Shoultz, 1982).

WHO CHOOSES?

by Bill Mitchell

Parents are a strong, stablizing force in a child's life and play an important role in helping the child develop self-confidence and a sense of independence. Parents of a child with disabilities typically want to protect the child, an instinct based primarily -- but not exclusively -- on a realistic knowledge of the child's limitations.

In the article that follows, the author discusses the need for young people with disabilities to be involved, as much as possible, in making decisions that affect their lives. He also discusses ways in which families affect their child's ability to take risks, make decisions, and live with the consequences.

Bill Mitchell works in the Governmental Affairs Office of the Association for Retarded Citizens (ARC) in Washington, D.C.. Currently, he is involved in a project funded by the Department of Housing and Urban Development to provide technical assistance in the fi[illegible] and design of housing for people with disabilities.

He came to Washington on a fellowship with the National Council on the Handicapped, during which time he wrote a paper on developing leadership in the disability rights movement.

Mr. Mitchell grew up in Atlanta, Georgia, where he attended public schools. He later graduated from Georgia State Un[illegible] with a Bachelors degree in Philosophy. Before coming to Washington, he worked as a counselor for students with disabilities at Georgia State University and as the staff advocate for the Georgia Advocacy Office.

Mr. Mitchell has a mobility impairment.

Historically, people with disabilities, both individually and in groups, have had few opportunities to exercise choices in their lives. In his book, *From Good Will to Civil Rights: Transforming Federal Disability Policy* (1984), Richard Scotch observes that "disabled people generally have not spoken for themselves, and public policies have typically dealt with their needs in ways shaped by stereotypes of dependency."

The lack of involvement of people with disabilities in decision-making at the policy level has its roots in the lack of participation in decision-making at the individual level. Decisions affecting people with disabilities have frequently been made by others. Those disabled early in life have gone from having parents make decisions for them to having doctors, social workers, or rehabilitation counselors make decisions for them. Those raised in segregated facilities have found their chances of making their own decisions restricted even further. No wonder then, that when confronted repeatedly with the message that they must learn to take responsibility, many people with disabilities feel confused and unprepared.

What are the barriers to exercising choices? Based on my observations and experiences with other people with disabilities, I have identified three barriers that I believe restrict opportunities for young people with disabilities to learn to make their own decisions:

1. Overprotection

Ironically, those who care most about individuals with disabilities may be among the obstacles to their gaining the experiences necessary to exert more control over their lives. Typically, most parents, but particularly parents of children with disabilities, feel the need to protect their children from the pain of failure and rejection. Yet, as they mature, children will be exposed to situations that require them to make choices and abide by the consequences.

As a part of growing up, youngsters will be out in their environment -- "hanging out" with the neighborhood kids, exploring the woods beyond the back yard, or stopping at the corner store on the way home from school -- out from under the watchful eye of a parent or other authority figure. It is during these times that children begin to learn more about their own capabilities and limitations and to feel a sense of autonomy.

In some cases, the combined effect of parental concern and environmental barriers may lead to a situation in which a child with a disability is never out of the house unless in the presence of a parent or another adult. The natural tendency of parents to protect their children is reinforced by the reality of the difficulties present in the immediate environment. Parents of children with disabilities often do not have a basis of comparison for determining what are acceptable versus unacceptable risks in the environment, and consequently may lack the reassurance needed to be able to allow their children their own "space" to find their way in the world.

In my own experience as a child having a mobility impairment and using a wheelchair, I got out a lot, explored my surroundings, and played with the neighborhood kids. These unsupervised experiences were among the most important in my life. I learned about relationships and about taking responsibility for my own actions, and generally broadened my perceptions of the world around me and how I fit into it.

Compare my experiences to those of a child in a residential facility. One situation reflects the society we live in -- the real world; the other reflects a society limited by restrictions that skew the child's perception of the world. When I consider my experiences of growing up in my own community and attending a neighborhood school where I had the same restrictions as other children, and then compare them to the experiences of acquaintances who have spent a significant part of their lives in residential facilities, it is not hard to account for the uncertainty many of them feel when confronted with challenges and opportunities.

Unfortunately, for many adults with disabilities, decisions to take on new experiences are influenced more by the degree of risk involved rather than the opportunities afforded by the experiences. And while my observations are unscientific, there seems to be a direct correlation between the degree of restriction these adults had as children and their fear of taking risks as adults. If you have been told much of your life that there are so many things that are too hazardous for you to do, and if you have never been given the opportunity to test the true limits of your capabilities, it wouldn't be surprising that you would be obsessed with security.

2. Low Expectations

Another barrier to the achievement of self-determination for many people with disabilities involves the low expectations that society has of them and consequently, that they have of themselves. As people with disabilities, we receive conflicting messages from different sources telling us: (1) that we are absolutely incredible for doing the most trivial of things; and (2) that whenever non-disabled people are around, we should let them help us do whatever we are doing because, surely, they can do it better. Instead of being encouraged to challenge ourselves to the point that we run a real possibility of failure, every effort is made to ensure that this doesn't happen. In the process, we are denied the thrill of a hard-earned success.

> *The importance of receiving the message that those who care about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated.*

Such negative messages about the capabilities of young people with disabilities can be countered by conscious efforts on the part of parents or other adults. As I was growing up, and to my complete consternation at the time, I was constantly challenged by my parents about whether I actually had done my best at different tasks. They attributed neither my successes nor my failures to my disability. In spite of what they may have felt inwardly, they never allowed me to feel that merely 'getting by' was good enough. While psychologists may debate the effects of such an upbringing on the young psyche, it did lead me to expect more of myself. Being challenged in this way also regularly required me to make choices for myself: I chose either to keep working at something to make it better, or I chose to declare the deed done.

The importance of receiving the message that those who care about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated. Having a 'good' failure is something everyone should experience. To know that it is a normal part of life and that people still care about you and believe in you can encourage you to get up and try again. Another effect of this kind of early learning is a sense of feeling more in control of your own destiny.

The more significant a person's disability is perceived to be, the more urgent it is that he or she be given every opportunity to exercise choices. Whether children with disabilities indicate their decisions through verbal communication, or with the aid of a pointer, a micro switch, or a communication board, it is important that they exercise the right to make choices, and in matters in which they can see the effects of their decisions.

3. Lack of Stable Support Systems

The lack of basic support systems to help one cope with failure can be particularly difficult for persons with disabilities. Discontinuity in some of the basic necessities of life, such as home, community, or friends, especially during the formative years, can add an additional barrier to the disabled person's freedom to make autonomous choices. In some cases, the person's need for security and safety in the environment may outweigh the benefits of assuming a new role in the community or taking on a new job that might further his or her career. While it may seem contradictory to the earlier point about overprotection, having a sense of belonging and a feeling of continuity in your environment is an important element in being able to challenge your capabilities. To be comfortable in taking risks, it helps to know that you've got a place to come home to after it's all over.

For parents, this means trying to provide stability and security for your children with disabilities to the greatest extent possible, while also giving them the freedom to explore. I believe that young adults with disabilities who are beginning to cope with increasing responsibilities and who are feeling overwhelmed by their choices can ease their anxiety by looking for small ways to bring stability to their world. For example, I love Mexican food, so at least once a week, even if the walls are crumbling around me, I go to the same familiar restaurant where they know me by name and always seem glad to see me. A small detail, perhaps, but it helps me gain perspective when other things are in flux. No matter how unstable an individuals's circumstances may be, being able to find even one small 'island of calm' that provides an anchor can do wonders for one's sense of stability.

I have listed three basic obstacles that young people with disabilities face as they strive to become adults with the confidence in their own capabilities necessary for exercising self-determination. All three barriers have the potential to limit opportunities in making choices. Parents can help their children to overcome these barriers by providing as many opportunities as possible that allow their children to take prudent risks and make decisions independently.

As I see it, there are two challenges to be addressed:

- o How to expose children with disabilities to more opportunities to make choices for themselves and to deal with the consequences of their choices; and
- o How to support and encourage young adults with disabilities as they explore their capabilities and options.

The answers that parents and other caregivers come up with today to these questions will determine the degree to which the next generation of young adults with disabilities is prepared to meet the challenges of a changing world.

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SELF-DETERMINATION AND NORMALIZATION AMONG ADOLESCENTS:

The Family as a Crucible of Values

by Rita A. Varela

Parents play an important role in teaching their children decision-making and problem-solving skills. The family can be viewed as a "training ground" where members learn how to adjust to feedback from others, how to make decisions, and how to receive guidance in what is expected of them (Summers, 1986).

In the article that follows, the author discusses the family as a source of values and support.

Since 1983, Ms. Varela has worked as a programmer analyst for GTE Data Services in Tampa, Florida. Her latest breakthrough is a book on statistical analysis, Victory Over Statistics, targeted to mid-level managers, MBA students, and grant writers. Before coming to GTE Data Services, Ms. Varela was a project coordinator for the American Coalition of Citizens with Disabilities in Washington, D.C.

She was born and raised in New York City, where she attended public school, and received her undergraduate degree at City College of New York. She has an M.A. from New York University and is working on an M.B.A. from the University of Tampa.

Ms. Varela has cerebral palsy.

Introduction

When I think about the term "self-determination," the overriding issue that comes to mind is the question of how to live your life in such a way as to actualize its full potential. I also associate the term with my days as a graduate student in political science, when the need to make a living and pay the rent was far from my thoughts and the diaries of libertarians such as John Stuart Mill and Henry David Thoreau absorbed me.

"Self-determination" is not a term I generally associate with rehabilitation literature. Yet, clearly, the term touches on two areas which are crucial to understanding both adolescents and disability: first, the role of the family as a crucible of values; second, the roadblocks facing disabled youth and the strategies families can follow to overcome them.

The Family as a Crucible of Values

Many authors have portrayed the family as a crucible of values from which we learn about winning, losing, cooperation, and conflict. I subscribe to this view with joy and fervor.

It was from my family that I first learned about planning, persuasion, and money. I don't remember when I did not know that a nickel was worth more than a penney, a quarter was worth more than a dime, and paper money was what you saved in the bank so that you could buy a house on Long Island. As for planning and persuasion, I still remember the arguments I had with my folks whenever I wanted to go downtown by myself. I grew up in New York City and was unable to use public transportation, so before I asked permission to go anywhere, I would go through the long, drawn-out process of calling a van service, negotiating over a day, a time, and a price, and investigating all the other details I had to memorize in order to prove to Mom that I could be trusted to take charge of my destiny. As I look back on those days and the hazards of urban life, I realize that the most extraordinary part of the arguments was that I won them.

To an adolescent, self-determination means the power to run your life your way. It means the right to make all the choices that adults in society can make. Before we dismiss this definition as simplistic, let me suggest that it has one virtue: namely, it mirrors the experience of transition from adolescence to adulthood. Though cynics may quip that parents won't stop telling their children what to do until they reach the age when they forget who their children are, parents do let go. The torch -- which in this case is the power of young adults with disabilities to make choices that once were made for them -- is indeed passed in the vast majority of cases. With that torch come lessons. Planning, persuasion, and introductory economics involve basic cultural and political information transferred from parent to child so early that we rarely identify when a child begins to scheme, negotiate, or barter. This transfer nearly defines traditional parenting.

Roadblocks and Remedies

The motivation underlying this transfer is empowerment. Parents want their child to enter the world of adulthood on an equal footing with all other adults. People with disabilities, however, often face roadblocks to full equality. Many roadblocks are institutional. Others stem from personal conflicts over values and identity which invariably befuddle adolescents.

All advocates know about the institutional roadblocks. We've all heard about parents who fight to get their child in school, who literally beg to get a dentist to treat their child, or who spend hours on the phone tracking down reliable transportation. The remedy for these roadblocks is equally clear: parent advocacy -- which means fighting, fighting, and more fighting. Personal roadblocks, however, are more complex.

A persistant sore faced by youth with disabilities concerns the problem of putting disability in perspective. Where does the disability end and the "you" begin? When things happen to you that you don't like, how much can be ascribed to you as a person and how much to your disability? Most kids with disabilities feel they are overprotected. So do most nondisabled kids. The difference is that in the former case, the kid is plagued by the thought, "If I weren't disabled, would it be different?"

Parent-child conflicts are a fact of life, not just a fact of disability life. Children with disabilities need to know that. They need to learn how the world works, how authority is transferred from parent to child, and how to get around obstacles. One of the best things parents can do to teach their children about the world is to widen the family's social circle. Though socializing is not always seen as either a priority or a simple matter by the parents of a child with a disability, teenagers with disabilities should see how other teenagers deal with their own conflicts with parents. Some teenagers with disabilities will conclude that the grass is greener in the next yard; others will not. In any event, a child can learn a lot by watching other children elbowing their way through adolescence. Parenthetically, watching other parents deal with teenagers can be instructive to grown-ups, as well.

An issue related to families and values concerns therapy on the homefront. More specifically, it involves the danger of parents becoming too focused on rehabilitating their child. Though I can't prove it scientifically, I firmly believe that the quality of your ethics, or, more precisely, the amount of time devoted to examining your ethical assumptions, bears directly on the quality of your life. I believe, for example, that all children should be taught it is wrong to steal apples. I do not feel that you should skip teaching this if your child hates apples or if your child is severely spastic, in a wheelchair, and unable to "reach" for an apple.

Though I do not advise parents to refuse to do therapy at home, I do suggest that parents set limits. The home must remain a home, not a rehab center. In that home, all children should be treated as future citizens, not as patients. And in that home, if a choice must be made between administering therapy and taking time to explain why it is wrong to steal, I urge the latter.

Summing Up

Perhaps the quintessential portrait of the family as a crucible of values occurs in *The Autobiography of John Stuart Mill* (1964). Mill describes taking long walks with his father and discussing famous books. His father used these occasions to offer "explanations and ideas respecting civilization, government [and] morality" (Mill, p. 29). That portrait sums up my view of what politics is all about, as well as my views of parenting at its best.

Self-determination? It means the right to make the kinds of choices that others have a right to make, and it requires equal access to public institutions. Parent advocacy? Parent advocates are the first in battle, tackling roadblocks which threaten a child's chances to participate in society and compete on an equal footing. The family? That's where you learn to plan and fight and scheme and dream about being the President of the United States. When you are a clumsy, sweaty, five-year-old, no one on earth will share those dreams with you except, possibly, your parents.

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Parent-child conflicts are a fact of life, not just a fact of disability life.

ANGER IN YOUNG ADULTS WITH DISABILITIES

Society often does not allow an individual to forget his or her disability. As a result, many young people with disabilities feel frustrated and angry.

The section that follows is taken from a letter written by a young man to a counselor who expressed concern over a 7-year-old client's anger at having cerebral palsy. The author of the letter, who has cerebral palsy, is presently studying to be a lawyer.

Dear ______________,

...I would like to add my own observations based on my perspective as an adult with cerebral palsy who was once an angry 7-year-old. When you stop to think of it, the anger the child feels is not unreasonable. Adults tend to overlook the fact that being able to walk and talk properly is much more important to a 7-year-old's satisfaction with life than it is for an adult. It may seem very unfair to the child to have been singled out for this problem. Furthermore, the adults around the child seem powerless to correct the problem.

Indeed, the child's anger may be a reflection of the disappointment that the adults around feel. The anger may be self-directed. I'm guessing at this child's feelings, based on my own experience and those of other people I have known who have this condition. The important thing is that the anger is interfering with the child's development.

In your letter [to me], you talk about teaching the child to accept the disability. Frankly, I think the notion of acceptance is overrated. Many of the people I know who have cerebral palsy and who have succeeded in becoming independent and contributing members of society are quietly angry. The difference is that they've learned to use their anger in constructive ways.

Your priority challenge as a counselor may be to help this child channel the anger away from self and others and toward the challenges presented by the disability. It may help the child to know more about cerebral palsy and about people with cerebral palsy.

It's important that the child knows that there are people in this world who have as much and more difficulty with walking and still manage to lead satisfying lives. It would be even better if the child could meet some adults with cerebral palsy who are living in the community, and learn more about the activities that people with disabilities can enjoy (J. Murphy, [personal communication], June, 1987).

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TIM BECOMES AN EAGLE SCOUT

by Bud Fredericks

Having role models may be one way to dissipate some of the frustration, anxiety, anger, and lonliness that many young adults with disabilities feel. Role models need not be superheroes, but rather people with disabilities who have accomplished goals that are important to them.

The article that follows describes a young man whose determination has led him to realize personal aspirations that man [illegible] never attain -- a strong sense of dignity and self-worth.

The author of this article, Bud Fredericks, is a research professor at the University of Oregon in Monmouth. He is the father of four grown children and is active in the Association for Retarded Citizens.

The following is an excerpt of an article from Exceptional Parent, Volume 17, No. 2, March, 1987. (Reprinted with permission from the author.)

Boy Scouts, Girl Scouts, Campfire, and similar groups for youth offer excellent opportunities for children with disabilities to participate in recreational activities with those who are not disabled. Often, in larger communities, separate units are established to accommodate those with disabilities. This is a story of what happen when integration occurs. It is also the story of what happens when a person with disabilities speaks for himself.

On April 21, 1986, Tim Fredericks was awarded the rank of Eagle Scout in Troop 161, a regular Boy Scout Troop of Philomath, Ore. (population: 2,500). One of the guest speakers at that ceremony had the following to say:

> "The State of Oregon spends millions of dollars annually to maintain those with disabilities in separate work facilities and in institutions.
>
> This community demonstrates how to integrate someone who is disabled into the mainstream of its society. Troop 161 could be a model for all other Boy Scout troops."

Choosing a Project

Tim Fredericks has Down syndrome. Yet his entire Boy Scout career of eleven years was spent in regular Cub Scout dens and a regular Boy Scout troop.

Tim met the requirements for the twenty-one merit badges necessary for the Eagle rank, but most important was his Eagle project, which he independently chose. His desire was to speak at school assemblies and tell other students what it is like to be disabled. Eagle projects must be approved by the Boy Scout district. In this case, the district was quite enthusiastic about the project's possibilities and wrote an encouraging response to Tim's request. The next step for Tim was to prepare the speech and write letters to school principals requesting the opportunity to speak.

Tim reads at about the third-grade level, and he prints anything he writes. He can neither read nor write cursive lettering, nor does he adequately compose and write at the same time. Therefore, Tim and his family developed a technique for all of his correspondence. Tim dictates what he wants to say while one of his parents prints his words. Tim then copies the dictated material. Tim's dictation over the years has become quite fluent, and he does not tolerate any editing of his ideas. He occasionally tolerates a suggested word or phrase change.

Writing a speech was more complex, however. Tim had many things he wanted to say to students who are not disabled and had no difficulty dictating these ideas over a period of two weeks. I suggested organizing the speech by subjects: school, work, friends, etc. Tim agreed, and all the ideas for each subject were grouped. Tim then added and deleted. Finally, a speech emerged.

The speech Tim gave was initially planned to be given to two or three high schools and junior high schools or elementary schools in the immediate area. He ended up by speaking twenty-seven times to more than 2,500 people. The speech he gave follows:

Tim's Speech

My name is Tim Fredericks. I am handicapped because I have Down syndrome. I was born with Down syndrome. Down syndrome people have an extra chromosome. Nobody knows why we have this extra chromosome. All of you have forty-six chromosomes. I have forty-seven. Would any of you like my extra chromosome? I would be glad to give it to you if I could.

I would like to tell you what it is like to be retarded. I am doing this so that you might be able to understand people like me.

School is a good place to learn, but I don't really like to go to school. I am a slow learner. I have a hard time spelling. Some of your teachers tell me that you have a hard time spelling, and you don't have my problem. I have trouble reading. Everyone tells me that I read about the fifth grade level. I hate to write letters and to write in my diary because it is hard for me to write.

After I graduate from school, I hope to live in an apartment with a good friend. I also hope to have two or three part-time jobs. I have two now that I get paid for. I work at Ark Animal Hospital every morning for two hours. I have to be there at 7:15. I work at Vandehey's Cabinet Shop three afternoons a week. I have been working now for more than a year at both jobs.

I do chores at home. I have to take care of all the animals, twelve chickens, three cats, a dog, three goldfish and a horse. That's a lot of mouths to feed.

I also help my Dad cut wood. I take care of my own room, and I help my Mom vacuum. She says I do a better job than she does. And she is right!

I love music, but I like hard rock best, but my Mom doesn't.

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I have a hard time explaining how I feel, but I feel the same way you do.

The hardest thing for me is when people make fun of me or ignore me. For instance, I went to a dance a few weeks ago, and no girl would dance with me. Can you imagine how you would feel if that happened to you? Well, I feel the same way.

Kids on the bus used to make fun of me. That used to make me mad.

I have a girlfriend, but she goes to a different school than I do. I don't get to see her too often. She is handicapped too. I have other handicapped friends, but my best friends are Chris and Mark Weaver. They have been my friends for five years. I think they really like me, and I like them.

I feel good when people talk to me or are friendly to me. That's one of the things I like about Boy Scouts. The boys accept me as I am. They know I am handicapped, but it doesn't make any difference. I am a scout just like them. It takes me longer, and I have to work a little harder to get my merit badges, but I get them done.

That's one of the reasons I am here. I am trying to be an Eagle Scout. I only have three more merit badges to go. My Eagle Scout project was to tell you about myself. I hope I have done that. I want to thank the principal, the staff, and students for letting me come and talk to you.

If anyone would like to ask any questions, I'll try to answer them, but if I can't, my Dad is here, and he can help me.

The Students' Reaction

And what was the reaction of the students? When he gave his speech to the school assembly of his own high school, the introduction by the principal was brief and noninformative: "Tim Fredericks is going to tell us something about his Eagle Scout project."

Tim stood before the student body of 400 with the microphone a little too close to his mouth so that his voice boomed throughout the auditorium. This was Tim's first speech, and so we as parents had little idea of what the reaction might be. The speech lasted approximately ten minutes. When he finished speaking, there was a spontaneous cheer from the student body, and all were on their feet applauding and cheering. Teachers were wiping tears from their eyes. One teacher said to Tim's mother, "We all needed that. Thank you."

Tim had been integrated into the high school for four years and had many friends who were not disabled, but the majority of the student body merely accepted him without really knowing much about him. However, after giving the speech, Tim said that everyone spoke to him.

Speaking to Elementary Students

It was fascinating to watch Tim give this speech, which was slightly edited from the one above, to elementary school students. The usual scenario went as follows: Tim would be introduced to approximately 100 students who would be sitting around the floor in a library or in some other general meeting room in the school. He would give his speech. At the conclusion of the speech, when he asked for questions, there would be a few seconds of silence followed by one hand of a student braver than the others. The question was usually quite simple. "What is your favorite music?" Tim would answer, and two more hands would be raised. Twenty minutes later, after a continuous give and take during a question period, half the student body would have their hands raised wanting to know more about Tim and what it is like to be handicapped.

We do not know the full effect Tim has had by being his own spokesperson, although many people have shared their personal reactions with us. We do believe he has made many more students and adults aware of the competencies that people with disabilities can have, and that those with disabilities are, first and foremost, people.

Ω

Suggestions for Parents: Helping Children Achieve Self-Determination

Being aware of the significance of self-esteem and decision-making and problem-solving skills in a young person's overall development does not necessarily mean that parents and professionals know how to how to encourage the growth of these skills. The following suggestions for how parents and others can help children and young adults with disabilities develop a sense of self-worth and self-sufficiency have been developed from readings in disability literature and from conversations with individuals with disabilities.

- Treat your child with a disability as a capable human being by encouraging and supporting his or her efforts to explore, take healthy risks, and try out new situations.
- Provide opportunities for self-awareness by focusing on your child's strengths and the qualities that make him or her special and unique.
- Let your child know that you enjoy spending time with him or her. Try to really listen when your child shares thoughts and experiences with you.
- Share your family stories, histories, and traditions with your child to help the child understand that he or she is a member of a family circle, with a permanent place in the larger scheme of things.
- Provide opportunities for interaction with others of different ages and backgrounds to help your child develop social confidence.
- Help your child experience success by encouraging him or her to build on known strengths and abilities.
- Acknowledge your child's efforts toward a goal, not just the final product or accomplishment.
- Have realistic expectations; don't expect so much that your child is set up for failure or frustration, or so little that you communicate a lack of faith.
- Let your child take responsibility for his or her own actions.
- Acknowledge your child's presence. Include your child in discussions with family and friends. Don't interfere unnecessarily to answer questions that were directed at the child.

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- Give your child a chance to grow into a unique adult. Avoid using labels such as "shy," "lazy," or "clumsy" to describe your child.
- Respect your child's need for privacy and time alone. Don't intrude unless it is absolutely necessary.
- Promote your child's assertive (not aggressive) behavior as well as respect for others. Being assertive is an excellent way for your child to avoid being exploited or taken advantage of.
- Encourage your child to practice and use basic coping statements to handle difficult emotions, such as anger, jealousy, or fear, but by all means, encourage their expression. (An example of a coping statement might be: "I can do this. I'll be just fine." or, "I really feel upset, but I need to stay calm.")
- Acknowledge your own sense of self-worth, when appropriate. Your healthy self-image will be a good model for your child.

There are many resources available to help parents understand their role in helping their child with disabilities learn to achieve self-determination. Many such resources are listed at the end of this *Transition Summary*.

As you face your responsibility as a parent, a teacher, or a professional in helping a child with disabilities achieve self-sufficiency, remember that learning to be independent is a difficult task for all young adults. Likewise, it is sometimes difficult to earnestly encourage a child's independence: letting go is one of the most difficult tasks that parents face. What is important to realize is that all children, regardless of their strengths or weaknesses, have to try many times -- and sometimes fail -- before they can gain the self-assurance and sense of personal worth that comes with adulthood.

Ω

This document was developed by Interstate Research Associates, Inc. pursuant to Cooperative Agreement #G0087C3051 with the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

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NICHCY would like to thank our Project Officer, Helene Corradino, at the Office of Special Education Programs, Office of Special Education and Rehabilitative Services, U.S. Department of Education, for her time in reading and reviewing this document. We also would like to thank Jim Murphy for his valuable insight and support in developing this document.

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Magazines For and About People with Disabilities.

Disability Rag, Box 145, Louisville KY 40201. Phone (502) 459- 5343 [TDY]. (A bi-monthly publication written by people with disabilities that covers the whole spectrum of disability rights.)

Legislation to Watch: The Disability Rights Bill.

As of this publication, this bill is pending before the House and Senate. It is sponsored by Congressmen Major Owens (D-N.Y.), James Jeffords (R-Vt.), Tony Coelho (D-Calif), and Silvio Conte (R- Mass.), and Senators Tom Harkin (D-Iowa), and Lowell Weicker (R-Conn.).

If passed, this bill would give individuals with handicaps the same rights afforded the disadvantaged and other minority groups under other existing Civil Rights legislation. For more information, contact Bob Tate at (202) 226-7532.

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ORGANIZATIONS

American Association of Disability Communicators, c/o National Organization on Disability, Suite 600, 910 16th St., N.W., Washington, DC 20006. (An organization concerned with disability issues and seeking improvement in disability communications. Publishes a quarterly newsletter, the AADC News.)

The Beach Center on Families and Disability. Contact Gary Brunk, The Beach Center on Families and Disability, The University of Kansas, Lawrence, KS 66045. Phone (913) 864-4950. (A federally funded national rehabilitation research and training center on families and disabilities. The purpose of the center's research, programs, and training is to advance the rights of people with disabilities at every age as well as the members of their families to have enduring and supporting relationships with each other in their homes, neighborhoods, and communities.)

The Disability Rights Center, 1346 Connecticut Avenue, N.W., Suite 1124, Washington, DC 20036. Phone (202) 223-3304. (A center established to advocate for the rights of all persons with disabilities. Publishes information on understanding disability, employment discrimination, and other topics. Write the center for a price list for the publications.)

The Disability Rights Education and Defense Fund (DREDF), 1616 P St., N.W., Suite 100, Washington, DC 20036. Phone (202) 328-5185 Voice or TDD. (A national nonprofit organization run primarily by people with disabilities. Offers information on the civil rights of people with disabilities. Publishes *Disability Rights Review*, a quarterly newsletter.) The national office is located at 2212 6th St., Berkeley, CA 94710.

Mainstream, Inc. , 1030 15th St., N.W., Suite [illegible]10, Washington, DC 20005. Phone (202) 898-020[illegible] (A National non-profit organization that works with corporations, state, local, and federal government, educators, and rehabilitation professionals to move persons with disabilities into the workplace. The organization sponsors conferences and disseminates publications on employment.)

National Self-Help Clearinghouse, 25 West 43rd, Room 620, New York, NY, 10036. Phone (212) 642-2944 (A national information and referral service for people seeking or wanting to create a self-help group.)

People First International, P.O. Box 12642, Salem, OR 97309. Phone (503) 378-5136. (A self-advocacy group of teenagers and adults with developmental disabilities. People First exists in 20 states. Addresses and phone numbers of existing offices available through the Salem, OR address.

The Research and Training Center on Independent Living, BCR-3111 Haworth Hall, University of Kansas, Lawrence, KS 66045-2930. Phone (913) 864-4095 [Voice/TDD]. (A center established to help people with disabilities live more independent lives. Conducts research on issues in the independent living field. Produces materials from studies, research, and training activities.)

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Appendix L
Making Contributions

- Giving a massage
- Volunteering time
- Making a gift
- Pitching in recycling
- Sticking up for someone
- Helping someone move
- Doing someone a favor
- Helping with yard work
- Caring for children
- Hugging someone
- Sitting with someone who's sick
- Sewing or mending as a favor
- Helping with light housework
- Walking a neighbor's dog
- Doing community service
- Giving or sending flowers
- Offering help if someone needs it
- Helping a neighbor shovel snow
- Working on a political campaign
- Taking care of animals or plants
- Visiting someone in the hospital
- Lending books, tapes, or videos
- Holding the door open for someone
- Inviting a (new) neighbor over for dinner
- Running errands for someone else
- Lifting things with or for a neighbor
- Receiving packages for a neighbor
- Offering good thoughts or prayers
- Noticing or commenting on an improvement
- Watering someone's lawn while they're gone
- Assisting public broadcasting in fund-raising
- Spending time with someone who's lonely
- Giving somoeone a piece for their collection
- Driving somoeone to the doctor, store, etc.
- Remembering a special occasion, throwing a party
- Stopping by regularly to see how someone's doing

- Participating in a local park's beautification effort.
- Writing letters or placing phone calls to help out
- Ushering at an event or volunteering at a booth
- Asking if a friend needs something at the store
- Acknowledging someone's expertise, talents, or gifts
- Helping with small repairs around someone's house
- Admitting a repair or utility person for someone else
- Offering help finding needed numbers and resources
- Sending a card – thank you, valentine, birthday
- Cooking for others or packing a lunch for someone
- Offering friendship and support to someone having a bad day
- Passing along to someone else items no longer used
- Looking after a house or apartment while owners' are away
- Sharing news of a bargain, job, news item of interest to another
- Having a standing date for lunch with a friend at a local retirement home
- Taking a picture of someone in their setting or at a special event

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Appendix M
Conversation Start-Up Kit

Ideas to assist people who have trouble knowing appropriate ways to strike up a conversation.

Riding on a Bus

Conversation with a stranger:

1 Does this bus stop at ———, Street? Thank you.

2 Pardon me. Could you tell me what time it is? (or some other information query)
Thanks. I was wondering if I'd be late for my appointment.

3 How do you like the weather today?
I like it *or* I don't like it because ——— .
I hope it changes tomorrow. *or*
I hope it stays the same tomorrow.

Conversation with someone you want to get to know better:

1 I sure like that ——— you have. I've been looking for something like that; where did you get it?

2 Would you mind if I sit by you? *or*
May I please sit by you? *or*
I'd like to sit here, would you mind?
(If no) Thanks, anyway. (smile)
Oh. Well then, I'll sit over here.

3 I noticed that you ride this bus every day. Do you enjoy it? *or*
Where do you get off the bus?

In a Store, Library, or Restaurant

Conversation with a stranger:

1 Do you know if there's a restroom here? (or a drinking fountain or a public telephone.) Thank you.

2 Do you know where the ——— are located? (example: *crackers*)
(Further description) You know, the kind that ——— .
I need them for ——— .

3 Could you help me with something? I need (or I want) to go upstairs, and I don't know where the escalator is.

(checking out or clarifying) Oh, do you mean. ——— ? *or*

I think I know what you mean; you mean *or*

Is this what you're saying? Is this the right direction?

Conversation with someone you want to know better:

1 Do you happen to know anything about ——— (a product)?

I'm trying to decide between ——— and ———, and I don't know which to choose.

2 Did you notice that oranges are on sale today? *or*

How do you like the new shopping carts?

(Examples: something unique or appealing or interesting, a change, a hot tip)

3 Do you know when this place closes?

Do you know if there's a bus stop (or a coffee shop) nearby?

At a Church, School, Social, or Sports Gathering

Conversation with a stranger:

1 Is there a ——— nearby?

- Drug store
- Bus stop
- Subway
- Pencil sharpener
- Coat room
- A coat rack

2 Is it OK if I ——— ?

- Sing loud
- Go in late
- Leave early
- Bring a guest
- Go dressed like this
- Don't have the right change
- Haven't got a ticket (or reservation)

3 Do you know where I can get a ——— ?

- Hymn book
- A drink
- Some popcorn
- Some refreshments
- Program

4 Would you mind showing me ——— ? (pointing it out) *or* Would you consider going there with me?

Conversation with someone you want to know better:

1 May I have a copy of ——— ? *or*
Is it OK if I copy ——— ?

- Your speech
- Your poem
- The article
- Your idea
- The instructions, directions
- The assignment
- The schedule
- Your map

2 Do you have ——— I could borrow? *or*
May I borrow ——— ?

- A pocket knife
- A pen/pencil
- A pad to write on
- A nickel, quarter
- Your binoculars
- A needle
- A flashlight
- Your book/tape

3 Could I have ——— ?

- Your telephone number, address
- Another chance
- Fifteen minutes or your time
- Your bracelet to look at (purse, ID card, ring, scarf, glove, briefcase)
- One of your flowers
- A tissue
- Some tape
- A paper clip

4 Would you be willing to share your ——— ?

- Bench
- Table
- Blanket
- Peanuts
- Popcorn
- Water
- Pew
- Program
- Sandwich
- Locker
- Newspaper
- Hand lotion

5 I'd like to ——— if that's OK with you.

- Save you a seat
- Call you sometime
- Come over to see you
- See you again

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Appendix N
Additional Resource Ideas

Creating Community: A Catalogue of Ideas

- Organize a neighborhood yard sale, spring cleanup, or dump run.
- Participate in networks: weight watchers, ethnic associations, recovery groups, recycling centers, environmental groups, societies, volunteer organizations, political groups, watching or participating in athletics, fan clubs, big brother/sister.
- Fix up a house or yard.
- Create a community center, a playground, community recreation program, thrift store, flea market, community talk radio.
- Create or join groups/clubs: Hiking, biking, photography, book reading, horse riding, boating, sewing, pet or animal training, pottery making.
- Share the cost and use of land, a vacation home, condominium, RV.
- Become affiliated with a spiritual or religious group.
- Share catalogs and order things together: vitamins, sale catalog items, bulk foods, etc.
- Two households share cost and use of items: vacuum, bicycles, camping equipment, tools VCR machine.
- Create a slide show (or a series of slide shows) with individuals contributing slides from their own collections.
- Invite people over for: pancake breakfasts, games like charades or Pictionary , birthdays/celebrations/parties, open house, making Christmas cards or Valentines, Easter Egg decorating/hunt.
- Develop a lending library of books, tapes, records, videos.
- Exchange skills of a trade, craft, or hobby. Exchange services and skills with others: mentoring, apprenticeship, tutoring.
- Rent out things that you buy: bicycles, video machines, canners, juicers, etc.
- Do potluck dinners, barbecues.
- Make ice cream and have everybody bring ingredients for something to put on it.
- Attend self-help group meetings.
- Start or join a co-op: food, housing, child care, respite care, child-watch.
- Share a garden or agricultural project.

- Special projects: canning, food drying, making root beer/ sasparilla, baking Christmas cookies, fix-up projects, quilt making.
- Traveling and trips: zoo, special places, aviary, concerts, movies, camping, outings.
- Share rides or become part of a car pool.
- Assist in group efforts: community celebrations/ festivals, fund-raising events, disaster clean-up, sub for Santa, adopt-a-highway, neighborhood crime prevention.

Community Resources

Recreation and Leisure

- Golf course
- Movie theatre
- Novelty shop
- Parks
- Volleyball
- Riding stables
- Amusement parks
- Gyms
- Multi-purpose centers
- YWCA/YMCA
- Zoo
- Campsites
- Gardens
- Museums
- Ice cream parlors
- Television
- Art galleries
- Spectator sports
- Video rental
- Bowling alley
- Pools
- Planetarium
- Skating rinks
- Resorts
- Winter sports
- County recreation
- Game room or arcade games
- Local national & state parks
- Wilderness areas
- Photography
- Social circle
- Plays, concerts
- Water sports
- Picnic areas

Routine/Community Life

- Library
- City/county building
- Post office
- Buses, depots
- Airport
- Cabs
- Laundromat
- Motorcycles
- Public telephones
- Grocery store
- Fire station
- Police station
- Train stations
- Travel agencies
- Cars/carpools
- Bicycles
- Public restrooms
- Driver's license

Shelter, Money, Possessions

- Residential options
- Social services field offices
- Department stores
- Hardware stores
- Motels, hotels
- Malls
- Shoe store
- Thrift shops
- Convenience stores

Spirituality/Service

- Place of worship
- Nature
- News: TV and Radio
- Magazines
- Music
- Volunteer Organizations
- Newspapers, Books,

Work/Money

- Sheltered employment
- Job Service
- SSI office
- Community centers
- Department of Labor
- Banks
- Comnty. based employment
- Medicare/Medicaid office
- Vocational rehab office
- Credit unions

Physical/Biological

- Restaurants, coffee shops
- Food stamps
- Dental office
- Medical offices
- Barber, beauty shops
- Special equipment retailers
- Physical therapy
- Hospitals
- Spas
- Yoga/Aerobics
- Drug/alcohol abuse
- Meals on Wheels
- Community cafeteria
- Doctor's office
- Chiropractor
- American Red Cross
- Occupational therapy
- Clinics
- Alternative health care
- Rehabilitation
- Weight training
- Counselor, therapist

Rights

- Legal Center
- Mental Health Center
- Hospice
- Mental Retardation Assoc.
- DD Council
- Police
- Consumer groups
- Lawyer/Attorney
- Planned Parenthood
- National, state, & local Arcs
- Dept. of Social Services
- Legislative coalition
- Vocational rehab services
- Professional associations

Relationships: Friends, Family Social Life

- Dances
- Dates
- Clubs
- Relatives
- Agencies
- Parties
- Big Brother/Big Sister
- Neighbors
- Child care
- Counseling Center

Mental Stimulation

- Talking books
- Hobbies
- Respite care
- Community college
- Evening classes
- Personal interests
- Continuing education
- University

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Transparencies

- Self-Advocacy
- Empowerment
- Interdependence

Read

- Chapter 2, Section 1:
  Encouraging Self-Advocacy
- Appendix D: *Advocacy: Noun, Verb, Adjective or Profanity?*
- Appendix E: *Confessions of a Paraprofessional*

Discuss

- Role of the paraprofessional as an advocate
- Personal experiences as advocates
- Lessons learned by the professional and their relationship to your experiences
- When enabling attitudes are or aren't appropriate

Essential Attitudes & Beliefs Necessary to Promote Self-Advocacy?

How to Negotiate

- Present your needs
- Discuss reason for your request
- Discuss example situations
- Express needs one at a time
- Explain how this will affect your life
- Rehearse your presentation
- Use appropriate body language

- Passive behavior
- Aggressive behavior
- Assertive behavior

How to Self-Advocate in Difficult Situations

- *Complaints?*
  Go to the source and state the facts.
- *Criticized?*
  Listen, accept constructive comments, and keep it in perspective.
- *Conflict?*
  State the problem and listen to other perspectives.
- *Complimented?*
  Accept it.

- *Read:*
  Appendix F: *Out of My Old Life and Into My New One*
- *Discuss:*
  Michael's situation and examples of self-advocacy
- *Share:*
  Similar experiences
- *Think About:*

a What Michael's life might have been like before he attained the level of independence of which he was capable.

b What this article says to paraprofessionals working with people with disabilities.

c What it says about the limitations people place on each other.

There are laws that protect individuals with disabilities and their families for:

- Work
- School
- Home

4.1

- Americans with Disabilities Act (ADA)
- Section 504 of the Rehabilitation Act of 1973
- Individuals with Disabilities Education Act (IDEA)
- Public Law 99-457
- MN Rule 3525.2925: Use of Behavioral Intervention with Pupils

- *Read:*
  Appendix J: *Who Can Teach Change Better?*
- *Think About*:
  How do you view yourself as a paraprofessional?
- *Discuss:*
  Can you see your role as also one of advising individuals toward independence?

- *Complete:*
  “Friendship Quotient”
- *Write:*
  Comments & questions, if any, under each statement
- *Discuss:*
  Biases about friendships between persons with and without disabilities

6.1

Helping build connections involves:

- Finding opportunities
- Interpretation
- Accommodation

- Time
- Intensity
- Intimacy
- Reciprocity

7.1

Issues for Persons with Disabilities

- Developing friendships
- Developing acquaintances
- Developing membership
- Keeping in touch
- Being part of a family
- Having a partner
- Being a good neighbor

Friends Give and Receive

- Information
- Feedback
- Assistance in decision-making
- Emotional support
- Material aid and service
- Access to others
- Companionship

8.1

Suggestions for Facilitating Friendships

- Survey the situation
- Review individual's day
- Estimate how much facilitation is needed
- Determine what you can do
- Think about who would be best facilitator
- Explore ways to use natural situations
- Follow-up on situations
- Disappear

MAPS: *Making Action Plans*

1 Ask key questions to establish direction

2 Target people to develop specific plans

10.2

PFP: *Personal Futures Planning*

1 Identify capacities
2 Identify a planning group
3 Clarify a personal future
4 Identify obstacles and opportunities
5 Generate strategies
6 Make commitments
7 Take action
8 Reflect on what the group is learning

3

Module Three

Promoting Self-Advocacy and Facilitating Friendships and Socialization Skills for Individuals with Disabilities

Prepared by
Institute on Community Integration (UAP)

UNIVERSITY OF MINNESOTA
The College of Education
and Human Development

Module Three

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Published November, 1995.

The paraprofessional training module *Promoting Self-Advocacy & Facilitating Friendships and Socialization Skills,* in the series *Strategies for Paraprofessionals Who Support Individuals with Disabilities,* was prepared at the Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota.

The development of these materials was supported in part through the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), grant #84029F20009 and the Administration on Developmental Disabilities (ADD), U.S. Department of Health and Human Services, grant #90000302. The opinions expressed herein are those of the authors and do not necessarily reflect the position of the U.S. Department of Education or the U.S. Department of Health and Human Services. This project is a collaborative effort between the Institute on Community Integration, Hutchinson Technical College, the Minnesota Department of Education, and the Minnesota State Board of Technical Colleges.

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Acknowledgments

The Advisory Committee of the Federal Paraprofessional Training Grant offered suggestions and support for the development of this module. The Institute on Community Integration at the University of Minnesota and the Hutchinson Technical College, working in collaboration on this project, would like to acknowledge and thank the members of the Advisory Committee for their efforts. The committee members are:

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Introduction

An Introduction to the Series

This series should be useful to paraprofessionals and paraeducators in education as well as direct service staff in community agencies in preparing for a career or in upgrading skills while already employed. Skills needed by individuals working under a variety of titles are often similar. Our focus is on those individuals working in education, but most of the information contained in this series is appropriate for others; please feel free to adapt it where needed.

The Need for Today's Paraprofessionals

The need for paraprofessionals to work with persons who have disabilities has been growing in recent years. Increasing numbers of persons with a range of disabilities are now living in small residential settings in our communities, attending regular classes in neighborhood schools, holding jobs in local businesses, and participating in community recreation and social activities. There is a great need for paraprofessionals to provide the services and supports these individual need for community living.

By employing paraprofessionals, services for persons with disabilities are able to expand and improve the quality of assistance they provide. Some of the benefits paraprofessionals offer service agencies and consumers are:

- Expanded learning opportunities for persons with disabilities.
- More individualized attention and instruction.
- Increased opportunities for individuals with disabilities to observe and learn appropriate behaviors.
- Increased planning time for educators, supervisors, and others.
- Improved staff morale.
- Better monitoring and evaluation of persons with disabilities.
- Greater consistency in services.
- Improved parent-school relationships.
- Greater involvement of persons with disabilities in education and other settings in the community at large.
- Transportation assistance for individuals with disabilities.
- Vocational skill development for individuals with disabilities.

The Role of Today's Paraprofessional

Paraprofessionals who work with individuals with disabilities have a variety of roles and definitions, depending on the environment in which they work. The Minnesota Department of Education (MN 3525.0200, Subp. 9b) definition states that a program assistant or pupil support assistant provides services to students only under the direct guidance and direction of a regular or special education teacher or related provider, and those services must be:

- To enhance the instruction provided by the teacher or related staff in academic instruction, physical or behavior management programs, transition, and other integrated activities.
- To supplement instructional activities or to provide extended practice in instances in which the support assistant has had training from a special education or related services staff, and continues to receive ongoing direction and support from a special education teacher.

From the National Resource Center for Paraprofessionals in Special Education and Related Services (City University of New York) comes this definition of a paraprofessional:

A paraprofessional is an employee:

- Whose position is either instructional in nature or who delivers other direct services to individuals and/or their parents.
- Who works under the supervision of a professional staff member who is responsible for the overall management of the program area including the design, implementation and evaluation of instructional programs and the individual's progress.

Paraprofessionals provide services in the following areas:

- Educational programs
- Physical therapy
- Occupational therapy
- Speech therapy
- Recreation programs
- Early intervention and preschool programs
- Social work/case management
- Parent training/child-find programs
- Vocational training programs and job coaching
- Community programs
- Transition

Paraprofessionals are typically different from professionals in the amount of education, certification required for the job, degree of responsibility, and extent of supervision required.

Because the support of paraprofessionals is so essential to the success of individuals with disabilities, this series is dedicated to improving and enhancing skills for paraprofessionals.

About the Series

Whether you have years of experience working with persons who have disabilities or are just beginning, there are probably many questions you have about the role of a paraprofessional. Some concerns and questions will be very specific to your work setting, while others will be more general. This series, *Strategies for Paraprofessionals Who Support Individuals with Disabilities,* will cover both.

This curriculum is primarily for paraprofessionals who are (or will be) working in educational settings (i.e., special and general education). It will, however, also be useful for those in direct service settings, such as vocational programs and residential settings.

The *Strategies for Paraprofessionals Who Support Individuals with Disabilities* curriculum has four general, or core, training modules and three specialized modules. The core modules, designed for all paraprofessionals, are:

- Module 1: The Paraprofessional: An Introduction
- Module 2: Providing Cross-Cultural Support Services to Individuals with Disabilities and Their Families
- Module 3: Promoting Self Advocacy and Facilitating Friendships and Socialization Skills for Individuals with Disabilities
- Module 4: Positive Behavior Strategies for Paraprofessionals

The three specialized modules that address competencies needed in specific types of service settings are:

- Module 5: Early Childhood: The Role of the Paraprofessional
- Module 6: Working with Individuals Who Are Medically Fragile or Have Physical Disabilities
- Module 7: Transition: The Role of the Paraprofessional

Each module is designed to stand alone, so you may select any one that best meets your needs. However, it's recommended that everyone begin with Module 1 because it provides a basic framework for work as a paraprofessional and for the material covered in all the other modules.

The training you are about to begin will not only address the current reality for paraprofessionals working with individuals with disabilities, but more importantly, the challenges for the future in your career as a paraprofessional. Paraprofessionals aren't expected to have a total understanding of all the concepts in these modules, but the paraprofessional who has a working knowledge of these core concepts will be most effective.

Guiding Principles

Each module emphasizes six basic guiding principles for paraprofessionals working with individuals with disabilities. Those principals include:

- The individual with a disability is the ultimate locus of control and is the most important member in the decision making process.

- The family is the other primary locus of control. Family involvement is essential in any decision making process.
- The team concept is essential in setting up a plan with an individual. This team includes the individual, the family, and all those working with the individual, including the paraprofessional. The paraprofessional is an essential link between what is and what can be for the individual. The best follow-through on any plan comes from teamwork.
- The community should be the basis for all training, as much as possible. This means that, whether offering real-life examples in the classroom or working in real life situations in the community, the focus must be on the most natural setting and support possible. This is essential so the individual can make connections between what is being learned on a daily basis and the real world. This will help the individual generalize the experience to similar situations in his or her life.
- Inclusion is the goal. This means that individuals with disabilities should be included in the mainstream of society – work, school, and recreation. Devotion to such a model will create the most positive results for the individuals and society as a whole. Inclusion suggests that we can and will all benefit by learning to work and live side by side with each other.
- The most effective paraprofessional will be the individual who has a good self-esteem and is able to be assertive. The assertive paraprofessional is able to ask for support and guidance from staff.

About You: The Adult Learner

We know that the adult learner learns differently than younger learners. This training reflects that understanding. In *Strategies for Paraprofessionals Who Support Individuals with Disabilities* we respect these principles about you, the adult learner:

- You are capable and eager to learn new information.
- You have voluntarily given your consent to become a part of this training, and are spending valuable time and money in order to participate.
- You have a rich range of experiences. Therefore you learn best when new information is built upon your past knowledge and experiences. That's why we will do exercises to help you synthesize the old and new information together.
- You come to a new learning situation as a self-reliant learner who has a good idea of how you want and expect to learn.
- Your willingness to learn is based on a combination of outside forces (family, kids, job, etc.) and inside forces (your anxiety, excitement, fears, etc.). All these factors are going to affect your feelings about learning.

- You come into new learning with your own agenda. You know what you want to get out of the training.
- You have set aside time and reorganized priorities to make this learning part of your already-busy life.
- You expect and genuinely appreciate a facilitator or instructor who is well-informed and well-prepared.
- You need to get actively involved in the learning exercises to get the most out of this curriculum.
- You want to apply what you learn to your own situations. That's when it has real meaning for you.
- You need a safe, comfortable environment in which to learn.
- You want to establish networks with others who are also interested in paraprofessional skills.

Because of these facts about you, trainers will:

- Review and ask questions about what you know.
- Respect and view you as a resource.
- Create a comfortable environment.
- Expect you to take responsibility for your own learning.
- Plan opportunities to practice new skills during class.
- Give examples of how to apply information.
- Use a variety of types of instruction.
- Provide ways to evaluate training.
- Use alternate methods to help you understand.
- Give information in a logical sequence.
- Give time for you to share your experiences.
- Give you the chance to get know other paraprofessionals.

After the Training

You will leave this training with more information about paraprofessionals than you had when you started. It's important to remember that no matter how much knowledge you have about your job, the individuals you work with are your greatest trainers. Each one is unique and has his or her own interests and needs. The greatest responsibility you have is to listen to those interests and needs, remember what you have learned, ask what is needed, and use that information in your working relationship and responsibilities.

Therefore, use this training as a basis and build your skills from this point, drawing upon each setting and individual. Whether client, student, teacher, supervisor, principal, director, or superintendent, you will learn from each. With each setting and situation your confidence, ability, and skills will continue to grow. Remember, this training is only as good as the degree to which you use what you learn; seek assistance so you can "do what you know."

1

Chapter One

Introduction to Self-Advocacy

1 **Introduction**
1 **Section 1 Self-Advocacy**
8 **Summary**
8 **Questions to Ponder**

Introduction

This module is designed to help the paraprofessional facilitate the ability of individuals with disabilities to determine for themselves what they want and need in their lives. It will help you encourage the exercise of self-advocacy skills in the individuals you serve.

Upon completing this chapter, you should be able to:

- Define *self-advocacy, empowerment,* and *interdependence.*
- Recognize your role as a paraprofessional in the self-advocacy process.
- Demonstrate an ability to promote both self-advocacy and empowerment.

Section 1

Self-Advocacy

In recent times, many terms have been used to describe the individual pursuit of independence by persons with disabilities. A list of buzz words around this topic have been developed, none of which are clearly defined. Three terms used to describe this topic are *self-advocacy, empowerment,* and *interdependence.* These terms are defined below:

Self-Advocacy

Self-advocacy is the ability of an individual to know what he or she needs and wants, and then based on those needs and wants, make personal choices. Among the choices is that of asking for support and assistance in order to live and work as independently as possible. It can also be defined as what a person does to communicate (advocate for) his or her own needs or to protect his or her interests or rights. In order to do this, the individual must understand his or her personal strengths and weaknesses. He or she must know what accommodations are needed, based on personal strengths and weaknesses. Self-advocacy is based on one's ability to answer the following four questions:

- What do I want?
- What do I need? (as defined by the individual)
- What do I like?
- What do I dislike?

In *Promoting Self-Advocacy* by Mary Powell and Joan Shoepke (1993), self-advocacy is summarized this way: "Self-advocacy is empowerment. It's not a single act, but rather a process which grows with nurturing. The goals to help the person to fully develop his or her potential for a regular life with regular choices. It can occur in individual or group situations."

Empowerment

Empowerment has been defined in many ways. Two examples include: "Enabling people to obtain the skills, knowledge, and abilities necessary to make their own decisions and gain control of their own lives. Empowerment means leading independent, productive lives" (Robert R. Davilla, former assistant secretary of OSERS). According to the Minnesota Governor's Council on Developmental Disabilities empowerment is defined as "processes whereby individuals achieve increasing control over various aspects of their lives and participate in the community with dignity."

Interdependence

Interdependence is mutual dependence. It means depending on one another. The individual has the ability to know personal strengths and weaknesses, to know what he or she can do independently, and to know how to ask for assistance. It means the individual not only asks of and "takes" from the environment (including the relationships that are part of that environment), but is also asked of and contributes to the environment. It's a level of "determination" one would hope for with all individuals, with or without disabilities.

Depending on the environment you work in, one of the above terms may be used more than another.

The Paraprofessional's Role in Self-Advocacy

No matter what term is used to describe an individual's quest for independence, the paraprofessional and other members of the team have important roles in enabling people to self-advocate. As stated in *Shifting Patterns* (1992): "At a personal level, people can develop the capacities and competencies of empowerment and self-determination only within themselves. *People empower themselves.* Others can assist individuals to gain the skills, knowledge, capacities, and allies they will need to take control of their lives, create and take advantage of opportunities, and overcome barriers."

When parents of individuals with disabilities were asked in a focus group what tips they would give paraprofessionals about encouraging independence in their son or daughter, they advised:

- Watch the individual with the disability. Let him or her take the lead, then help where or when needed.
- Hold yourself back. Don't jump in to do what the person can figure out to do for him- or herself.
- Give extra help when needed.
- Teach the individual to ask for help.

- Teach peers how to encourage independence by being role models, and by telling individuals how to act to address their own needs, rather than always jumping in and helping.

You are, or will be, working with people who have unique and sometimes very great needs, and the natural response is often to jump in and help. But self-advocacy is about choices and giving the individual the respect and integrity to always have the opportunity to make personal choices, as everyone deserves.

Consider this poem and think about self-advocacy. What do you think about the poem? How does this relate? How did you feel after you read it?

The Language of Us & Them

We like things.	They fixate on objects.
We try to make friends.	They display attention-seeking behavior.
We take breaks.	They display off-task behavior.
We stand up for ourselves.	They are non-compliant.
We have hobbies.	They self-stim.
We choose our friends wisely.	They display poor peer socialization.
We persevere.	They perseverate.
We love people.	They have dependencies on people.
We go for a walk.	They run away.
We insist.	They tantrum.
We change our minds.	They are disoriented and have short attention spans.
We have talents.	They have splinter skills.
We are human.	They are...?

Adapted with permission from Mayer Shevin, in J. Pearpoint, M. Forest, & J. Snow, *The Inclusion Papers: Strategies to Make Inclusion Work*, 1991.

What Kind of Behavior Are You Promoting?

Listed below are many headings that describe various types or styles of behavior. It's important for you to think about where you "fit in" with these styles. The activity on the following page will help you understand the behaviors you rely on in your work as a paraprofessional.

Activity: Modeling Roles

Think of the phrases that promote self-advocacy below. Think of the phrases that encourage dependency. Think of how you respond to individuals in your work as a paraprofessional. Then circle the twelve phrases which describe how you view your role as a paraprofessional. Which skills do you want to be modeling?

As a Nurturer

- Accepts, allows, encourages
- Seeks out and acknowledges the ideas/expertise each person offers
- Invites
- Requires
- Sees potential in others
- Brings out creativity in others
- Creates a safe environment
- Trusts
- Ignores undesirable qualities in others
- Communicates privately
- Shows others how to sharpen skills
- Self validates
- Validates others
- Defers

As an Innovator

- Experiments; takes risks
- Resists change
- Sees, creates, focuses on possible options
- Is open-ended
- Suggests trying another way or idea
- Assists others in expressing their views
- Accepts differing opinions
- Acts defensively
- Sets up group problem solving and advises
- Brainstorms
- Initiates negotiations
- Recognizes need for more information
- Suggests how or when others might locate alternatives
- Locates alternatives
- Uses resources freely
- Recognizes the need for help

- Caretakes, rescues
- Includes individual in deciding what is needed
- Sees the value of learning from what may seem a mistake or bad experience
- Sees challenges as opportunities to grow
- Deals with "problem" situations

As One Who Cooperates

- Believes in own personal power
- Manipulates
- Empowers others
- Collaborates, cooperates
- Sees that we are all in it together
- Focuses on "being with"
- Shares credit with others
- Values private time and space
- Is always available
- Creates a support network
- Becomes unproductive, overwhelmed, immobilized
- Appreciates and allows silent times
- Feels a need to fill in silences with words; likes to hear self talk

As a Positive Person with High Self-Esteem

- Celebrates self and others
- Apologizes
- Sees people as developing, growing
- Trusts own intuition; encourages others to do the same
- Imagines things as they could be
- Is positive and hopeful about the future
- Acts burned-out, cynical
- Believes that when offered a variety of choices, people will make the best personal choice
- Appreciates humor in self and others
- Takes it all too seriously
- Laughs with self and others
- Perseveres; shows courage

As a Assertive Speaker/Listener

- Speaks easily, tactfully, candidly
- Hides behind jargon
- Uses non-verbal, as well as verbal skills
- Pays attention to requests

- Models gentleness and kindness with self or others
- Models "asking for what I want"
- Initiates or confronts
- Relays back what is seen, heard, felt
- Asks before giving feedback
- Gives feedback, whether or not recipient is agreeable

As an Open-minded Individual

- Treats others as equals
- Accepts persons rather than forming preconceived ideas
- Refuses to put people in slots, categories
- Uses judgments, labels
- When listening, refers issues to the appropriate persons
- Blaming
- Shows courage
- Values differences, disagreements
- Values only sameness, likeness

As a Delegator

- Organizes, prioritizes for self, encourages others to do same
- Models and supports taking responsibility for self
- Takes responsibility for others
- Listens and watches, focusing on strengths, skills that will help person help him- or herself
- Seems controlling
- Encourages independence, risk
- Encourages dependence
- Provides ideas to define, clarify
- Acts as a source of information only when appropriate
- Delegates, with agreement
- Does only for others and feels overloaded

Adapted from *Using Natural Supports in Community Integration* by E. Curtis, New Hats, Inc., P.O. Box 57567, Salt Lake City, Utah, 84157. Telephone 801/268-9811.

Shifting Patterns, Beliefs, and Attitudes

Shifting Patterns is a comparison of the ways individuals with disabilities are often considered versus the ways individuals are considered. Read the "from" and "to" items below and think of these comparisons as you go.

From	To
• No choice	• Choice
• Feeling hopeless	• Feeling hopeful
• Self-doubt	• Belief in self
• Self-blame	• Promoting the possible
• "They owe me"; blaming others	• I am responsible for the future; take control of my own life
• Seeing deficits	• Seeing strengths
• Professionals know better than parents or lay people	• People have different kinds of knowledge
• "We" choose for "them"	• Consumers choose for themselves
• Power over	• Power with and among
• Exclusive ("us and them")	• Inclusive ("all of us")
• Differences as inadequacy	• Differences as assets
• One cultural perspective	• Multicultural perspective
• The system sets the agenda for individuals and families	• Individuals and families setting and pursuing own agendas
• Focus on information to individuals and families so they'll know what experts think is best and act appropriately	• Focus on skills, competencies and knowledge so individuals and families can set and pursue what they think is best
• Focus on changing individuals and families	• Focus on individuals & families changing the system and public policy
• Focus on self-improvement	• Focus on self-determination, self-creation, advocacy and improvement
• Professionals planning for people	• Individuals and families planning for themselves
• A professional team, to which individuals and families may be invited	• A team of family and friends, to which staff who are close to the individual may be invited
• Focus on services into which the individual can fit	• Focus on how the world needs to work so the individual is a member of and contributor to the community

• A preoccupation with test scores, problems, and weaknesses	• A preoccupation with strengths and capacities
• Having one's best interests represented by others, usually families	• Making choices & representing one's own interests
• Being seen and treated as a client	• Representing oneself as a citizen and person with rights
• Life skills training	• Assertiveness/advocacy training

Adapted with permission from the Cornell Empowerment Project and *Shifting Patterns* developed by the Minnesota Governor's Council on Developmental Disabilities, October 1992.

Summary

Understanding and being able to promote self-advocacy and empowerment in an invaluable tool for paraprofessionals working with individuals with disabilities. This chapter defined *self-advocacy, empowerment,* and *interdependence* and discussed your role in the self-advocacy process. It also helped identify behaviors paraprofessionals rely on in their work and offered a comparison of the ways people with disabilities are viewed versus the way "normal" people are considered. These concepts can be applied when assisting individuals with disabilities to become more empowered in all area of their lives. Chapter Two explores ways to put these principles into practice.

Questions to Ponder

- In what ways do you currently promote self-advocacy and empowerment?
- In your job, what are ways you can promote self-advocacy and empowerment?
- What are some ways others encourage and support your empowerment?
- What are three ways individuals with disabilities are often viewed in comparison with individuals without disabilities? Think of ways you can help change this in your role and through your behaviors.

2

Chapter Two

Promoting Self-Advocacy

9 Introduction
9 Section 1 Encouraging Self-Advocacy
15 Section 2 The Art of Negotiation
18 Summary
19 Questions to Ponder

Introduction

How can you as a paraprofessional encourage self-advocacy? What are your attitudes about self-advocacy? How do you respond to it? How do you encourage negotiation? This chapter focuses on ways paraprofessionals can put self-advocacy into practice.

Upon completing this chapter, you should be able to:

- Identify ways you can encourage self-advocacy.
- Recognize your attitude about self-advocacy.
- Define ways people self-advocate.
- Demonstrate an ability to respond to self-advocacy.
- Identify steps you can use to help people learn to negotiate.

Section 1

Encouraging Self-Advocacy

Those who encourage behavior that leads to self-advocacy are true bridge-builders for the future of individuals. Some ways you can encourage self-advocacy are:

- Take time to build trust networks so the individual has confidence in his or her support system and feels the courage to self-advocate.
- Give responsibility to the individual.
- Show appreciation for contributions the individual makes at home, school, and work.
- Ask for the individual's opinion. This gives the individual the understanding that their experiences and ideas have merit and are valued.
- Encourage the individual to participate in problem solving and decision making at all times.
- Accept mistakes.
- Guide the individual through situations until he or she can advocate for him- or herself.
- Get to know the individual and his or her strengths and weaknesses so you can help him or her make connections.
- Start with small goals and work into the big ones.
- Be patient and take time with the individual. Self-advocacy can be scary business.
- Give up control. Let events take their own course and just "happen" when you feel the individual can handle his or her own advocating.

- Don't fix or change things. Let the individual work things out on his or her own.
- Don't teach the community how to "accommodate". Teach the individual to ask for the specific and appropriate accommodations needed.
- Be responsive.
- Have a commitment to the importance of self-advocacy.
- Be creative with both decisions and judgments.
- Understand that your role in promoting self-advocacy is, at best, unclear. You will be learning with each individual what will be the best techniques to support his or her self-advocacy.

"You Create It" Scenario

Pick one choice from each of the items below and then create your own scenario:

The individual is:

- A child under five
- A teenager
- A young adult in college
- An adult in a residential setting

The individual has:

- Never advocated for self before
- Has advocated unsuccessfully
- Is a good self-advocate
- Is aggressive in advocating
- Is passive and doesn't know needs

The individual has:

- A supportive, nurturing family
- A passive, uninvolved family
- A demanding, aggressive family
- No family or family support

The individual is:

- Ready to self-advocate
- Is frightened to self-advocate
- Doesn't know what to do
- Can advocate with support

You have worked with the individual:

- Daily over a long period
- Never
- Only occasionally
- Only in self-advocacy training

The individual:

- Trusts you
- Knows you're patient
- Doesn't like you
- Has had good experiences with you in the past
- Has had bad experiences with you in the past

You are:

- Committed to self-advocacy
- An enabler
- Responsive and perceptive
- Dreading this part of your job

You and the individual are working on advocacy skills in:

- A work situation
- A school situation
- A home situation
- A neighborhood situation
- A relationship situation

"You Create It" Scenario by ______________________
Your Name

Now address the following questions based on your scenario.

- What was the specific situation?

- What I did to promote self-advocacy?

- What did the individual do to be a self-advocate?

- What accommodations needed to be made in the setting to facilitate independence?

- Who asked for those accommodations and how that was received in the setting?

- What part family members, friends, neighbors, teachers, or agency people played in the situation?

- What was the end result of the situation? Was it positive? Negative? How could the process have been better?

Activity: Evaluating Your Attitude

In order to promote self-advocacy, you must first evaluate your own beliefs and attitudes. Understanding how you react to individuals with disabilities will help you understand how the community at large reacts. It's also important to be honest with your feelings so that you can approach the issue of self-advocacy. If, for example, your honest belief is that individuals with disabilities have very limited capabilities on the job, and you're working as a job coach, you will probably not promote and encourage the individual's skills. On the other hand, you might behave very differently in that same situation if you felt the "sky's the limit." You would be more likely to help the individual accomplish whatever he or she wanted to accomplish. How you view people limits their ability to advocate and accomplish their goals. You must be honest about this before becoming a promoter of self-advocacy.

With this in mind, complete the following inventory about yourself and your attitudes and beliefs. Read the statements below. Check each statement you truly believe.

☐ I believe everyone (regardless of disability) has the right to achieve their goals and dreams.

☐ I believe that individuals with disabilities are entitled to reasonable accommodations that will help them achieve their goals.

☐ I also believe that there is a point beyond reasonable accommodations for which individuals should not have accommodations made.

☐ I believe individuals with disabilities have the ability to know what they want.

☐ I believe individuals with disabilities have the ability to make good choices for themselves.

☐ I believe individuals with disabilities have the ability to speak out for themselves.

☐ I believe individuals with disabilities must ask assertively for what they want and need.

☐ I believe it's important to understand your rights, your strengths, and your weaknesses in order to self-advocate.

☐ I believe that self-advocates can create a lot of conflict in their advocating, but sometimes that is a necessary part of the process.

☐ I believe my major role in advocacy is to guide, encourage, and support individuals toward their desired goals, but the true, effective advocacy must come from the individual him- or herself.

Find a partner and discuss the statements you checked. Compare your "beliefs" with his or hers. Do you differ significantly in your beliefs? Decide together which items you feel are essential to have checked to be a good promoter of self-advocacy.

Questions for Paraprofessionals to Ask Themselves When Promoting Self-Advocacy

The following are "thought" questions for you to read. After reading them, think about how you *really* feel about the questions and how you would answer them. You don't have to write your answers down but may if you wish. Pick two or three questions you want to discuss and form a small group and discuss your reactions or feelings about the questions. This exercise is meant to help you think about your attitudes toward self-advocacy, what you do to encourage self-advocacy, and maybe ways you could improve.

- Am I listening to the needs, interests, and desires of individuals or am I imposing my own point of view?
- Do I see the human growth and potential of individuals or do I see the "disability" and "limitations"?
- How do I react when an individual is his or her own advocate? Can I handle it?
- Do I have a need to control the individual's decision-making? Could any of my actions be considered a conflict of interest?
- Is it okay for individuals to question my point of view and or give me negative feedback about what I am doing?
- Is it okay for individuals to tell me they don't need me and can make their own decisions?
- Do my actions:
  - Increase the self-respect, self-confidence, and self-reliance of individuals so they feel comfortable taking risks?
  - Decrease dependence on me?
  - Teach individuals a process for making decisions and problem solving?
  - Involve individuals in activities that increase self-understanding and promote being the key player in personal decision making?
  - Encourage individuals to obtain a wide variety of information and points of view so they make informed decisions?
  - Recognize that anger is okay and even justified in many instances and encourage individuals to use that anger toward positive growth and societal change?

If you can answer *yes* to most or all of these questions, you're preparing individuals to become positive self-advocates.

How Do I Know if an Individual is Self-Advocating?

If you can answer *yes* to any of these questions, the individual is appropriately self-advocating. If the individual is doing the following, praise him or her for assertive behavior. If the individual isn't using these behaviors, encourage him or her to do so. Give examples of how this could be accomplished.

Is the individual:

- Asking me for specific help?
- Able to explain his or her disability to me?
- Asking me in a direct manner?
- Communicating slowly and in a manner that I can understand?
- Organized to ask me for specific assistance because he or she planned ahead?
- Clear about his or her specific needs?

- Asking for assistance that seems reasonable given his or her needs and the specific setting?
- Respecting my rights as a paraprofessional?
- Aware of his or her rights?
- Talking about ideas that would help and asking for my input?

Responding to a Self-Advocate

You now know the "cues" of someone who may be appropriately asking for assistance. But what steps do you take when an individual does ask for help? These steps may be useful in helping you develop a plan to support the individual.

- Listen to the individual explain the situation in which he or she is asking for assistance.
- Ask the individual for his or her ideas on possible solutions (accommodations or modifications).
- Talk over the possible solutions with the individual.
- Discuss the positives and negatives of each solution discussed.
- Make sure solutions being discussed relate to the disability area needing accommodation or modification. (Sometimes you may come up with solutions that would be nice but don't really relate to the specific needs of the individual and therefore aren't really considered "reasonable accommodations".)
- Arrive at a solution you can agree on. Be sure to include anyone else in the decision making that will be a part of carrying out the modification or accommodation.
- Set a time-line to implement a solution and follow up with an evaluation of the solution chosen.
- Make adjustments, if necessary, or continue of the solution is working to the satisfaction of the individual.
- Commend the individual for arriving at a solution. Remind him or her that you will continue to "be there" for him or her as needed for future issues and concerns.

Section 2

The Art of Negotiation

Learning to negotiate is an essential skill that will tie all the other pieces of advocating together for individuals with disabilities. Here are some steps that you can use and adapt with individuals to help them learn how to negotiate for what they want and need in a constructive manner:

- Introduce what you need to the person you need it from. Present your needs clearly.
- Discuss the rationale for your request. When you do this, remember to use your knowledge of your strengths and weaknesses, be specific, be consistent, and most of all, be believable. You will be believable when you state what you know about yourself in a clear, respectful, knowledgeable fashion.
- Discuss example situations where you will need what it is you're asking. In this way you're showing that you aren't "asking for the moon", but that at certain times and in certain situations, you have very specific needs, based on your strengths and weaknesses.
- Express the needs that you have one at a time (step by step) so that the individuals can understand them.
- Explain how this will make a difference to you in your life and in your ability to perform.
- Verbally (or otherwise, if necessary) rehearse your presentation/request. Use someone you trust as an audience. This will help build your comfort level.

To the best of the individual's ability, encourage him or her use the following body language:

- Face the person with whom you're negotiating.
- Use an appropriate voice tone.
- Use appropriate (positive) facial expressions.
- Use good body posture.
- Use good listening skills.

Adapted from *Self-Advocacy* (unpublished) by Steve Hazell and Rud Turnbull, University of Kansas.

Basic Human Rights and Responsibilities

Look at these seven situations in preparation for classroom discussion. Notice the difference between someone's rights and their responsibilities.

Situation 1

- **Right:** A person has the right to ask for what he or she wants.
- **Example:** John has the right to ask to borrow his mother's car.
- **Responsibility:** When asking for what he wants, John has the responsibility to state his request specifically and in a calm manner. He also needs to realize that his request may not be granted.
- **Example:** John asks his mother to borrow her car to go to the movies Friday night. His mother, however, has other plans for the car and refuses his request. John has the responsibility to accept his mother's answer, to not throw a temper tantrum, and possibly to discuss with his mother other options for getting to the movies.

Situation 2

- **Right:** A person has the right to try to change things that he or she doesn't like.
- **Example:** James doesn't like his job. He has the right to either try to change the conditions of his current job or find another job.
- **Responsibility:** When trying to make changes, James has the responsibility to state his concerns calmly and directly to the people in charge. Grumbling about a situation but doing nothing to change it is irresponsible behavior.
- **Example:** If James is unhappy with his job and would like to change the situation, he has the responsibility to talk directly to his boss about the matter. He also has the option to quit his job and find another.

Situation 3

- **Right:** A person has the right to make his or her own choices.
- **Example:** Jane has the right to choose what she will do with her life when she finishes high school.
- **Responsibility:** Jane has the responsibility to accept the consequences of her choice and to make sure her choice doesn't take away the rights of others.
- **Example:** After much thought, Jane, an eighteen-year-old high school student, decides she would like to be a construction worker when she finishes school. She knows, however, that her dad would like her to go to college. Jane has the right to choose whether she will go to school or work. She has the responsibility, however, to accept the consequences of this choice. In this case, two possible consequences might be finding a job and dealing with an upset parent. Jane has the further responsibility to make sure her choice doesn't take away the rights of others, including her dad. If Jane tells her

dad about her decision in a calm and direct manner, then she will be acting in a responsible manner. However, if Jane yells at her dad or lies to him, she'll be violating her dad's rights as a parent (among which is the right to be treated with respect).

Situation 4

- **Right:** Mary has the right to say "no."
- **Example:** Mary has the right to say no to a classmate if he asks her to do something that she doesn't want to do.
- **Responsibility:** When saying "no", a person has the responsibility to say it in a calm manner and without preventing other people from exercising their rights.
- **Example:** Mary's friend asks her to skip fifth hour English. Mary doesn't want to so she simply says "no." Mary doesn't need to explain her decision, but may if she chooses. By saying "no" to her friend in a calm yet firm manner, Mary stands up for her right. At the same time, she doesn't prevent her friend from exercising his rights.

Situation 5

- **Right:** A person has the right to privacy.
- **Example:** Anna has the right to have some privacy in the apartment she shares with two roommates.
- **Responsibility:** A person has the responsibility to express her desire for privacy and to make sure that by exercising this right it doesn't infringe upon the rights of others.
- **Example:** Anna shares an apartment with two roommates. She asks a friend, Luis, to come over to watch TV. Anna asks her roommates if she could use the family room for Saturday evening so she could entertain her guest. Marsha, one of her roommates, says it's fine with her because she's going out of town for the weekend. Rosa, the other roommate, says it's okay with her because she's working on an art project in her room.

Situation 6

- **Right:** A person has the right to make mistakes.
- **Example:** Terrell has the right to make the mistake of getting on the wrong bus. This may be unpleasant, but it isn't the end of the world. Making mistakes is one way people learn.
- **Responsibility:** When an individual makes a mistake, he has the responsibility to accept the consequences of that mistake.
- **Example:** If Terrell gets on the wrong bus and is late for work, he has the responsibility to explain what happened to his boss. He also has the responsibility to accept other consequences of his mistake, such as a reduction in pay.

Situation 7

- **Right:** A person has the right to be treated with respect.
- **Example:** Nadine has the right to have her teacher listen to her speak no matter how difficult it might be for Mary to express her ideas.
- **Responsibility:** Every person has the responsibility to treat other people with respect.
- **Example:** If Nadine's teacher is giving an assignment, Nadine has the responsibility to treat her teacher with respect. One way Mary can do this is by listening to what her teacher says rather than talking to her classmates. This shows respect not only for Mary's teacher, but also for her classmates who need to hear the assignment.

All individuals have rights and responsibilities for their behavior. The previous situations have shown in a variety of instances that individuals clearly have rights and with each of those rights comes the responsibility to act out those rights in an appropriate, respectful manner. Along with rights and responsibilities are also choices. Individuals have choices about how they will act out their rights and it's their responsibility to make those choices in an appropriate manner at all times in order not to infringe on the rights of others.

These situations were adapted with permission from *Self-Advocacy* (unpublished) by Steve Hazell and Rud Turnbull from the University of Kansas.

Summary

Understanding self-advocacy and negotiation, and the techniques to promote theses skills, are abilities that paraprofessionals can use to assist individuals with individuals with disabilities to become empowered. As a paraprofessional, being able to identify and reinforce self-advocacy skills facilitates the ability of persons with disabilities to determine what the want and need in their own lives.

This chapter discussed ways of promoting self-advocacy and negotiation for persons with disabilities. Activities provided you with opportunities to evaluate your attitudes concerning self-advocacy and ways you currently promote self-advocacy. Chapter Three explores what it takes to be a successful self-advocate.

Questions to Ponder

- What were your feelings when a person with disabilities self-advocated and you supported his or her efforts? How did you respond?
- What were your feelings when a person with disabilities self-advocated and you *didn't* support his or her efforts? How did you respond?
- In your own job, how have individuals with disabilities self-advocated?
- How do you promote negotiation skills in individuals with disabilities?

3

Chapter Three

What it Takes to Be a Successful Self-Advocate

21 Introduction
21 Section 1 Characteristics of a Skillful Self-Advocate
33 Summary
33 Questions to Ponder

Introduction

In order to support the self-advocacy of individuals with disabilities, you need to know the characteristics of a skillful self-advocate: the necessary behaviors, understanding one's strengths and needs, preparation, and practice.

Upon completing this chapter, you should be able to:

- Define the successful behaviors of a self-advocate.
- Identify passive, aggressive, and assertive behavior.
- Demonstrate effective self-advocacy techniques in difficult situations.
- Assist a person with disabilities to prepare for an individual planning meeting.
- Identify reasonable accommodations.

Section 1

Characteristics of a Skillful Self-Advocate

Many behaviors must be present for an individual to successfully self-advocate, and these skills and behaviors will be introduced in this section, along with activities designed to clarify the importance of these characteristics.

Behaviors of Successful Self-Advocates

A self-advocate is one who can:

- Take the initiative to talk with others in person.
- Tell the appropriate person about his or her disability.
- Make his or her needs clearly known.
- Ask to meet needs with an assertive (not aggressive) approach.
- Explain his or her strengths and weaknesses to others to receive appropriate services and who can ask for appropriate accommodations.
- Show self-confidence in describing his or her needs.
- Develop a positive relationship with people.
- Approach the situation calmly and with self-control.
- Supply information about his or her disability to those who will be working with him or her.
- Show respect to those from whom he or she is requesting help,

services and/or support.

- Plan ahead for needs (rather than asking at the last minute).

What other characteristics can you and the class think of?

- ____
- ____
- ____
- ____
- ____
- ____

As a paraprofessional, it's important for you to know what can be expected of the individual. When you understand the individual's abilities, you can help, train, and support the positive attitudes necessary for him or her to be a successful self-advocate. You can expect self-advocacy behaviors to some degree from all individuals. Therefore, it's important to separate things you do for the individual that are necessary, and those things that the individuals should be doing or asking for him- or herself.

You must be careful not to enable individuals to be inappropriately dependent upon you. *Enabling* means to do *for* the individual what he or she could or should learn *to do independently*. Sometimes it's difficult to determine what is enabling behavior and what isn't. The best step to take when you're not sure is to ask your supervisor, or better yet, observe and ask the individual. Notice his or her capacities and work from that point.

Discussing Strengths and Weaknesses

In order for an individual to be able to self-advocate, that person must know his or her personal needs. This means understanding one's strengths, gifts, and capacities and how to build upon these assets. It also means knowing one's weaknesses and limitations and how to accommodate or compensate for those areas. By learning about one's strengths and weaknesses, an individual can develop a strategy, in any given situation, for how to learn or accomplish the task in the best way possible for him or her.

As part of the team process, it's important to share all information including testing findings with the individual. As a paraprofessional working closely with the individual, it's important to share observations about how the individual appears to learn and cope with situations on a daily basis. It's important to encourage staff to share information about the individual (both strengths and weaknesses) with the him or her as a means of helping to develop a better understanding of self. In too many situations, the needs (especially the weaknesses) of individuals are discussed without their involvement. Too often extensive tests are given to individuals to learn their strengths and weaknesses and then never shared with the individual in an understandable way.

It's important to explore with the individual all aspects of his or her life. There are many areas of strengths all individuals have that don't show up on test performance or daily activities but are an important part of a person's life. These may be areas that can be used to compensate or accommodate the individual when observed as a "whole being". The best person to explore these strengths (capacities) and weaknesses (limitations) is the individual him- or herself.

An effective, simple way of exploring these areas with an individual is to collect all the information you can about the individual's strengths and weaknesses from a professional standpoint. Then ask the individual to gather and think about all the information on his or her strengths and weaknesses in all areas of life. Then get together, with the collective information, and make a chart together about including the combined information. Based on the combined information on the chart, you and the individual can work toward finding reasonable accommodations based on individual needs and capacities.

Pages 24 and 25 contain examples of charts you could complete with an individual with this combined information.

Passive, Aggressive, or Assertive?

Once people understand themselves by making a picture of their strengths, weaknesses, and needed accommodations, they are more prepared to start self-advocating. There are three ways individuals can express their needs: in a passive, aggressive, or assertive manner. It's very important for individuals to know and understand the difference between these three styles and which one will work the best in gaining the support they need. It's crucial for individuals to clearly understand the different ways of expressing needs and the best way to obtain the support they need. The three types of expression are defined as follows:

- **Passive Behavior:** This is when an individual knows he or she needs assistance but is either afraid to ask for help or doesn't really know how to ask. So rather than seeking assistance, he or she just ignores the need or waits passively hoping someone will step in and guess or assume the need.
- **Aggressive Behavior:** This is when an individual knows, or thinks he or she knows what is needed and demands service or asks in a very angry or aggressive way. This method doesn't respect the rights of others and is generally not accepted well by the person from whom help is being sought.

[*Continued on page 26*]

My Strengths and Capacities

Things I can do and am proud of doing:

In My Neighborhood

In School

In My Place of Worship

In My Social Life

On My Job

In My Clubs & Social Groups

Accommodations that help me be successful:

My Weaknesses and Limitations

Things I have more difficulty with and need support for:

In My Neighborhood	In School
In My Place of Worship	**In My Social Life**
On My Job	**In My Clubs & Social Groups**

Accommodations that help me be successful:

- **Assertive Behavior:** This is the behavior we are striving to develop in positive self-advocacy. It's exhibited when an individual knows what support/accommodations he or she needs in a given situation, know who to ask for assistance, and then asks in a clear, concise, polite manner. The assertive person knows his or her legal rights, but isn't rude or aggressive in having those rights meet.

Self-Advocacy in Difficult Situations

As the paraprofessional working with the individual closely every day, you can help him or her understand they are in charge of their own assertive behavior and sometimes they will encounter especially difficult situations. Techniques for them to use in handling those situations may include:

- When you have complaints, start with the source and state your facts. If you don't get satisfaction, go through the proper channels using available support, until the problem is solved.
- When you're being criticized, listen for the constructive comments about yourself, take them seriously, accept the criticism, but keep it in perspective so that you don't respond in a defensive manner.
- When you're involved in a conflict, state the problem and listen to the other person's perspective. Then brainstorm solutions and select the best choice together. Try the solutions, then evaluate it to see if it was effective. If the solution isn't working, make necessary changes.
- When you're complimented, accept the compliment without expecting more or feeling you must return the compliment.

Be Prepared

Once the individual knows what it takes to be a positive self-advocate, has an understanding of his or her strengths and weaknesses, knows the proper behavior (assertive) to self-advocate, and understands how to be in charge of his or her own behavior, the individual is ready to *get prepared!* This means that the individual has all the tools to advocate, but still needs some skills that you can help provide. The two remaining steps in getting prepared are:

- Sharing the appropriate information about him- or herself with others.
- Asking for accommodations or modifications based on this self knowledge and an understanding of legal rights.

The best way to help the individual use the information learned about him- or herself is to practice preparing for a meeting. Use your experience collecting information on the strengths and weaknesses charts to complete the following scenario as a exercise. You can use this format in the future when helping individuals prepare for meetings. By planning and organizing the individual's thought with him or her in this way ahead of time, he or she will be able to express his or her own needs in the meeting.

Scenario

Let's assume that Jon, an individual you have been working with, is preparing for an transition meeting. He will be graduating from high school and going to work. The following is the information you collected together.

- **Strengths and Capacities:** You and Jon have listed on the strengths and capacities chart that he's had a paper route in the neighborhood for five years and has mowed lawns for neighbors for three years. He has been successful on these jobs and has saved money in a bank account over the years. In school Jon has done well in industrial arts classes, has been on the swim team, and has done well in basic math concepts. He hasn't attended a church. In his social life, Jon has been involved with a group of kids throughout high school that also live in his neighborhood. Jon doesn't have a driver's license, but he takes the bus or rides with friends wherever he goes. In terms of clubs or groups, Jon has been in the swim club for three years. He appears to be well liked by both faculty and students.
- **Weaknesses and Limitations:** Jon has had several academic problems over the years, stemming from his disability. His reading skills are at about the fifth grade level. He has had trouble following complicated directions (both oral and written). Jon has been encouraged to be involved in church youth group activities but feels he has been teased by the group so he doesn't participate. He isn't able to drive and feels this has an impact on his social life. Jon hasn't had a job outside the neighborhood and has never had an indoor job.
- **Planning:** Based on this information, Jon is going to enter the planning meeting and make some decisions about the type of work he wants after high school. You, Jon, his parent(s), a psychologist, teachers, rehabilitation counselor will all be in the meeting. Jon will be asked to state the his experience, what he feels are his strengths and weaknesses, and what support (accommiodations/modifications) he will need on the job. Complete the following as a "cheat sheet" for the Jon in preparation for the meeting.

  My key strengths are:

My key weaknesses are:

My work experience includes:

The kind of work I am interested in:

The help I will need on the job:

Steps to Self-Directed Individual Planning Meetings

Once an individual is prepared, he or she can function successfully in his or her individual planning meeting and express personal strengths, weaknesses, and desires. Each individual you work with will be at a different level in his or her ability to participate in the meeting. Nevertheless, individuals should be made aware that this is *their* meeting and *their* opportunity to express personal dreams and desires.

Time needs to be spent with the individual prior to the meeting to explain what will happen, what his or her role should be, and how important it will be for him or her to express personal wants and needs in this group. As a part of the planning meeting, you, as the paraprofessional, can assist your supervisor and the individual in preparing the individual for his or her meeting by encouraging him or her to ask for and/or do the following steps in the meeting:

- State the purpose of the meeting.
- Invite everyone in the group to introduce themselves.
- Review past goals to bring everyone up to date.
- Ask for feedback from others in the group.
- State the individual's, family's, and institution/school goals.
- Encourage all to ask questions if they don't understand.
- Be open to different opinions.
- Have the opportunity to state the support he or she will need.
- Summarize the goals.
- Close the meeting by thanking everyone.
- Make a verbal promise to work on the goals until the next meeting.

If the individual has limited communication abilities, plan ways with the team that the individual can interact and participate in the meeting. Work with the individual ahead of time to help prepare him or her to participate as much as possible. Make sure that the individual's needs and wants are not overlooked just because of limited communication or intellectual abilities.

Adapted from *Self-Directed IEP Student Workbook*, Center for Educational Research, University of Colorado at Colorado Springs.

Deciding on Reasonable Accommodations

An important part of what it takes to be a successful self-advocate is to know what accommodations the individual will need to be successful in reaching his or her goals. Accommodations don't just refer to job situations. Individuals may need accommodations in social settings, schools settings, residential, neighborhood, or work settings. The kind of modifications or accommodations needed will vary depending on the individual. There's no list one can go through and pick the right accommodation to meet the needs of individuals in all settings. "Reasonable accommodations" describes what is needed to accommodate individuals with disabilities because it's language used in the Americans with Disabilities Act (ADA) which was enacted in 1990.

The best way for an individual to receive the accommodations he or she needs is to know what they are. This means knowing strengths and capabilities as well as weaknesses and limitations and also knowing what has worked in the past.

If an individual you're working with is very young or has recently acquired a disability, he or she may not have had enough experience to know what works as an accommodation for him or her in various situations. Some individuals who have had a lifelong disability also don't know themselves very well. Individuals will need you to offer suggestions about what accommodations might work. In order to make suggestions, you should first ask or have someone else find out for you:

- What are your needs in this situation?
- What help do you need from me or others?
- What environmental changes can we create to make this situation work for you?
- What types of needs do you have that we could solve with equipment/technology? (The individual may not know the answer to this but you may have ideas based on how he or she responds and your observation of the situation.)

Based on the answers you receive, develop a plan with the individual to try some accommodations and see what works. If it feels like you're "shooting from the hip," you probably are – but some of the best accommodations were designed this way. Deciding on reasonable accommodations isn't a science. Most of the best accommodations come from these kinds of brainstorming sessions. Successful accommodations are often inexpensive and effective.

Once the individual has had experience with you guiding him or her through the questions above, he or she will begin to feel comfortable determining his or her own accommodations without your guidance. When the individual reaches this point, he or she is ready to advocate in his or her own behalf.

What Are Reasonable Accommodations?

The following are examples of reasonable accommodations in learning situations for individuals with particular learning difficulties. These are typical accommodations requested in school and are just examples to give you an idea of what an accommodation may be in a given situation.

Accommodations for Reading Difficulties

- Have the textbook tape recorded, or do this yourself or have peers do it for him or her.
- Read the textbook to him or her or ask a peer to do it.
- Ask the individual if he or she would rather have directions read aloud, or tests read aloud to him or her.
- Ask the individual if it would help in understanding if he or she had an outline or brief set of directions to follow along to help focus attention.
- Ask him or her if extra time is needed to complete reading tasks.
- Show him or her how to highlight or underline the main points for clarification.
- Suggest that the individual let the teacher or others know if he or she is uncomfortable reading aloud in a group setting.
- Help the individual with reading skills on a individual basis.
- Help the individual to find a peer to help him or her review the important points.
- Teach the individual to work in a quiet area.

Accommodations for Writing Difficulties

- Teach the individual to use a spelling dictionary.
- Teach the individual to learn to use word processing with spelling and grammar checking features.
- Teach the individual to ask someone to proofread his or her work.
- Have the individual dictate written work.
- Suggest that the individual ask if he or she could present information in another way other than written, like a verbal presentation or a drawing.
- Suggest that the individual ask a peer to share his or her notes.
- Tape-record instructions or lectures to listen to later.

Accommodations for Math Difficulties

- Ask the individual to sit near the instruction or direction.
- Suggest that the individual ask for explanation of symbols and steps if he or she isn't sure.
- Teach the individual to write down mathematical processes step-by-step.
- Set up the individual working with a peer who can explain the math necessary to complete the task.
- Show the individual how to use graph paper to keep problems in line.

- Suggest that the individual ask for concrete examples when he or she doesn't understand.
- Suggest that the individual ask for additional time where math is involved.
- Teach the individual how to use a calculator.

Accommodations for Organizational Difficulties

- Teach the individual to ask for an outline of instruction, rules, directions, etc.
- Teach the individual to ask for a schedule of what is going to happen at the beginning of a class, or a job, or a series of instructions.
- Teach the individual to ask for instructions to be repeated if he or she didn't understand them.
- Teach the individual to ask to have instructions written down if needed.
- Teach the individual to ask for individual time with the instructor or supervisor (on a job) for further explanation if he or she doesn't understand what is expected of him or her.

These are just simple examples of accommodations that can be arranged. Always remember that the individual should initiate his or her own accommodations as much as possible. Your role, as a paraprofessional, is to support these efforts toward independence but not to discourage the individual's ability to seek out his or her own opportunity to achieve that independence.

Self-Determination Panel Discussion

You may decide it may be helpful to have a panel discussion in class or with the individuals with whom you work. The following questions may be used to ask the panel: use them to encourage discussion with visiting panel members about their experiences as self-advocates. You may also want to use these questions on the job when you notice that some individuals seem to be better able to express their needs than others. Asking questions, respectfully, can be a very useful learning experience for you in helping other less assertive individuals improve their skills.

- What was the hardest thing for you to learn as you worked to be a better self-advocate?
- Can you give me an example of a time when your efforts at speaking for yourself really paid off?
- Can you give me an example of when speaking up and asking for services or help backfired and got you into trouble?
- What one piece of advice can you give me about advocating, based on your experiences?

- What can I do as a paraprofessional on my job to facilitate self-advocacy among individuals with whom I work?
- Can you remember one person in your life who helped encourage you to self-advocate? Who was that? What did he or she do to help you?

Adapted from *Self-Determination: The Journey to Independence* developed by Michael Wehmeyer and Hank Bersani, Jr.

Summary

This chapter discussed characteristics of a skillful self-advocate. Specific behaviors were identified, including assertiveness, self-confidence, planning, stating needs clearly, and respect for others. A capacity chart was used to identify and build on self-advocacy skills. Passive and aggressive behaviors were also discussed – particularly why they aren't successful behaviors.

Questions to Ponder

- What are five behaviors of a successful self-advocate?
- Have you personally observed a skillful self-advocate? What made you feel he or she was skillful?
- Have you ever had an experience where you felt you were a skillful advocate for yourself but were not successful?
- How can you encourage individuals to advocate for themselves?

4

Chapter Four

Rights of People with Disabilities

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Introduction

In order to be an effective self-advocate, you not only need to demonstrate skillful behaviors, but also possess knowledge of the appropriate rights and laws. By having knowledge of such rights and being able to apply it in specific situations, you hold another key to empowerment.

Upon completing this chapter, you should be able to:

- Identify the rights of the self-advocate, the consumer rights statement, and the Resident Bill of Rights.
- Discuss the Americans with Disabilities Act, Section 504 of the Rehabilitation act of 1973, IDEA, and Part H of IDEA.
- Discuss the use of behavioral interventions.

Section 1

Individual Rights

People with disabilities have the same rights as any other human beings. In order for an individual to be able to self-advocate, he or she must understand his or her rights and it's your role as a paraprofessional to assist people in the understanding of these rights. The following are three examples of rights statements as published in the manual *Promoting Self-Advocacy* by Mary Powell and Joan Shoepke: the *Self-Advocacy Workbook List, Consumer Rights Statement,* and the *United Nations Universal Declaration of Human Rights.* When using these as examples, think about other rights that apply specifically to the individuals with whom you work.

Rights Statement 1: *Self-Advocacy Workbook List*

- The right to life.
- The right of choice.
- The right to freedom.
- The right to try to be happy.
- The right to make up your own mind.
- The right to choose the people you want to be with.
- The right to be listened to.
- The right to eat what you want.
- The right to go to bed when you want.

Adapted with permission from *We Can Speak for Ourselves*

Rights Statement 2: *Consumer Rights Statement*

Rights are the things that the law says you should get, like the training that you need to live and work like everyone else. You have many rights when you work here:

- You have the right to be by yourself when you want to be.
- You have the right to be treated well by staff.
- You have the right to a safe place to work where you won't get hurt.
- People do not have the right to say or do bad things to you or to keep you from eating or to take your money.
- You have the right to know the rules about working here.
- You need to know what to do when you don't like something.
- You have the right to speak up for yourself.
- You have the right to ask for an advocate, or someone to speak up for you.
- You can ask that a report about how you're doing be given to you, your family, or your advocate.
- You have the right to have your questions or concerns answered as soon as possible.
- You have the right to have a place to keep your things.
- You have the right to use a telephone for private calls.
- None of your rights can be taken away without a chance for you to tell your side of the story.
- You have a right to get the training you need to live and work more independently.
- You have the right to see a doctor when you need to and without waiting a long time.
- Staff cannot do things that might physically hurt you.

Adapted from *Read My Lips*

Rights Statement 3: *The United Nations Universal Declaration of Human Rights*

Whereas Member States have pledged themselves to achieve, in cooperation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore, the General Assembly proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

1 All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act toward one another in a spirit of community.

2 *A:* Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
B: Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self governing or under any other limitation of sovereignty.

3 Everyone has the right to life, liberty and security of person.

4 No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

5 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

6 Everyone has the right to recognition everywhere as a person before the law.

7 All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

8 Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

9 No one shall be subjected to arbitrary arrest, detention or exile.

10 Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of one's rights and obligations and of any criminal charge against him.

11 *A:* Everyone charged with a penal offense has the right to be presumed innocent until proved guilty according to law in a public trial at which one has had all the guarantees necessary for one's defense.
B: No one shall be held guilty of any penal offense on account of any act or omission which did not constitute a penal offense, under national or international law, at the time when it was committed. Nor shall a heavier penalty be im-

posed than the one that was applicable at the time the penal offense was committed.

12 No one shall be subjected to arbitrary interference with one's privacy, family, home or correspondence, nor to attacks upon one's honor and reputation. Everyone has the right to the protection of the law against such interference or attacks.

13 *A:* Everyone has the right to freedom of movement and residence within the borders of each State.
B: Everyone has the right to leave any country, including one's own, and to return to his country.

14 *A:* Everyone has the right to seek and to enjoy in other countries asylum from persecution.
B: This right may not be invoked in the case of persecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

15 *A:* Everyone has the right to a nationality.
B: No one shall be arbitrarily deprived of his nationality nor denied the right to change one's nationality.

16 *A:* Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
B: Marriage shall be entered into only with the free and full consent of the intending spouses.
C: The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

17 *A:* Everyone has the right to own property alone as well as in association with others.
B: No one shall be arbitrarily deprived of property.

18 Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief; and freedom, either alone or in community with others and in public or in private, to manifest one's religion or belief in teaching, practice, worship and observance.

19 Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontier.

20 Everyone has the right to the freedom of peaceful assembly and association. No one may be compelled to belong to an association.

21 *A:* Everyone has the right to take part in the government of one's country, directly or through freely chosen representatives. Everyone has the right of equal access to public service in one's country.
B: The will of the people shall be the basis of the authority of

government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

22 Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international cooperation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for one's dignity and the free development of one's personality.

23 *A:* Everyone has the right to work, to free choice of employment, to just and favorable conditions of work and to protection against unemployment.

B: Everyone, without any discrimination, has the right to equal pay for equal work.

C: Everyone who works has the right to just and favorable remuneration ensuring for oneself and one's family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.

D: Everyone has the right to form and to join trade unions for the protection of one's interests.

24 Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

25 *A:* Everyone has the right to a standard of living adequate for the health and well being of oneself and of one's family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond one's control.

B: Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

26 *A:* Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

B: Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance, and friendship among all nations, racial, or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

C: Parents have a prior right to choose the kind of education that shall be given to their children.

27 *A:* Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

B: Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary, or artistic production of which one is the author.

28 Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

29 *A:* Everyone has duties to the community in which alone the free and full development of one's personality is possible.

B: In the exercise of one's rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order, and the general welfare in a democratic society.

C: These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

30 Nothing in the Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

This section on rights was adapted with permission from *Promoting Self-Advocacy, Instructor's Guide* by M. Powell and J. Shoepke, presented by the Minnesota Association of Rehabilitation Facilities (MARF), the Minnesota Developmental Achievement Center Association (MnDACA), and Brainerd/Staples Regional Technical College (B/SRTC) as part of a collaborative grant from the Bush Foundation, 1993.

The Residents' Bill of Rights

The following Bill of Rights is another example of the rights mandated by law and provided especially for individuals with disabilities. You may see a version of these rights in many forms in different residential environments.

A: Purpose of the Residents' Bill of Rights

The purpose of the Residents' Bill of Rights is to identify the rights of residents in Minnesota's community residential facilities which are licensed as health care facilities and certified as intermediate care facilities for persons with mental retardation (ICF/MR). Services to persons with developmental disabilities should be based on individual interests and needs and be designed to preserve human dignity, and to protect both civil and human rights.

Home and Community Based Waiver programs use the Home Care Bill of Rights which may be obtained from the Minnesota Department of Human Services, 612/296-3971.

B: Introduction to the Bill of Rights

The following is the introduction which is included in the Residents' Bill of Rights:

This document describes the rights of residents in Minnesota's community residential facilities which are licensed as health care facilities and certified as Intermediate Care Facilities for person with Mental Retardation (ICF/MR). These rights are set forth in M.S. 144.651-2, and in Volume 42, Code of Federal Regulations, Sections 442.403 and 442.404.

Definitions: "Resident" means a person who is admitted to a non-acute care program including extended care facilities, nursing homes, and board and care homes for care required because of prolonged mental or physical illness or disability, recovery from injury or disease, or advancing age.

Public policy declaration: It is declared to be the public policy of this state that the interests of each resident be protected by a declaration of a Residents' Bill of Rights which shall include but not be limited to the following:

It is the intent of the legislature and the purpose of the Residents' Bill of Rights to promote the interests and well-being of residents of community facilities. No community program may require a resident to waive these rights as a condition of admission to the program. Any guardian or conservator of a resident or, in the absence of a guardian or conservator, an interested person, may seek enforcement of these rights on behalf of a resident. An interested person may also seek enforcement of these rights on behalf of a resident who has a guardian or conservator through administrative agencies or in probate court or county court having jurisdiction over guardianships and conservatorships. Pending the outcome of an enforcement proceeding, the community program may, in good faith, comply with the instructions of a guardian or conservator. It is the intent of this section that every resident's civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the program shall encourage and assist in the fullest possible exercise of these rights.

The resident is to be fully informed, as evidenced by written acknowledgment witnessed by a third party, prior to or at the time of admission and during the stay of these rights and of all rules and regulations governing resident conduct and responsibilities. A copy of the law is to be given to the resident. The interests of the resident and, where appropriate, guardians, next of kin, sponsoring agencies, representative payees or the public shall be protected by, but not limited to, the following policies and procedures:

C: Individual Rights

Listed below are each of the rights contained in the Residents' Bill of Rights.

The Right to Information About Rights

Residents shall be told at admission that there are legal rights for their protection during their stay at the program or throughout their course of treatment and maintenance in the community and that these are described in a written statement of the applicable rights and responsibilities set forth in this section. In the case of persons admitted to residential programs as defined in MN Statutes 253C.01, the document shall also describe the right of a person sixteen years old or older to request release as provided in section 253B.04, subdivision 2, and shall list the names and telephone numbers of individuals and organizations that provide advocacy and legal services for persons in residential programs. Upon receipt of this statement and a full explanation, the resident must acknowledge the receipt in writing. Residents already in the program must be provided with written amended statements if these provisions are changed. Reasonable accommodations shall be made for those with communicative disabilities and those who speak a language other than English. Current program policies, inspection findings of state and local health authorities, and further explanation of the written statement of rights shall be available to residents, their guardians or their chosen representatives upon reasonable request to the administrator or other designated staff person, consistent with Chapter 13, the data practices act, and section 626.557, relating to vulnerable adults.

The Right to Courteous Treatment

Residents have the right to be treated with courtesy and respect for their individuality by employees of or persons providing service in a community residential program.

The Right to Appropriate Medical and Personal Care

Residents have the right to appropriate medical and personal care based on individual needs. Appropriate care for residents means care designed to enable residents to achieve their highest level of physical and mental functioning. This right is limited where the service is not reimbursable by public or private resources.

Isolation and Restraints

A minor who has been admitted to a residential program as defined in MN Statutes 253C.01 has the right to be free from physical restraint and isolation except in emergency situations involving a likelihood that the resident will physically harm self or others. These procedures may not be used for disciplinary purposes, to enforce program rules, or for the convenience of staff. Isolation or restraint may be used only upon prior authorization of a physician, psychiatrist, or licensed consulting psychologist, only when less restrictive measures are ineffective or not feasible and only for the shortest time necessary.

The Right to Know Who is Providing Physicians Services

Residents shall have or be given, in writing, the name, business address, telephone number, and specialty, if any, of the physician responsible for coordination of their care. In cases where it is medically inadvisable, as documented by the attending physician in a resident's care record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative.

The Right to Know Who is Providing Services

Residents who receive service from an outside provider are entitled, upon request, to be told the identity of the provider. Residents shall be informed, in writing, of any services which are provided to those residents by individuals, corporations, or organizations other than their program. Information shall include the name of the outside provider, the address, and a description of the service which may be rendered. In cases where it is medically inadvisable, as documented by the attending physician in a resident's care record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative.

The Right to Information about Treatment

Residents shall be given by their physicians' complete and current information concerning their diagnosis, treatment, alternatives, risks, and prognosis as required by the physician's legal duty to disclose. This information shall be in terms and language the resident can reasonably be expected to understand. Residents may be accompanied by a family member or other chosen representative. This information shall include the likely medical or major psychological results of the treatment and its alternatives. In cases where it is medically inadvisable, as documented by the attending physician in a resident's medical record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative. Individuals have the right to refuse this information. Every resident suffering from any form of breast cancer shall be fully informed, prior to or at the time of admission and during her stay, of all alternative effective methods of treatment of which the treating physician is knowledgeable, including surgical, radiological, or chemotherapeutic or combination of treatments and the risks associated with each of these methods.

The Right to Participate in Planning One's Own Treatment

Residents shall have the right to participate in the planning of their health care. This right includes the opportunity to discuss treatment and alternatives with individual caregivers, the opportunity to request and participate in formal care conferences, and the right to include a family member or other chosen representative. In the event that the resident cannot be present, a family member or other representative chosen by the resident may be included in such conference.

If a patient or resident who enters a program is unconscious or is unable to communicate, the program shall make reasonable efforts as required under paragraph *C* to notify either a family member or a person designated in writing by the patient as the person to contact in an emergency that the patient or resident has been admitted to the program. The program shall allow the family member to participate in treatment planning, unless the program knows or has reason to believe the patient or resident has an effective advance directive to the contrary or knows the patient or resident has specified in writing that they do not want a family member included in treatment planning. After notifying a family member but prior to allowing a family member to participate in treatment planning, the program must make reasonable efforts, consistent with reasonable medical practice, to determine if the patient or resident has executed an advance directive relative to the patient or resident's health care decisions.

For purposes of this paragraph, "reasonable efforts" include 1) examining the personal effects of the patient or resident; 2) examining the medical records of the patient or resident in the possession of the program; 3) inquiring of any emergency contact or family member contacted under this section whether the patient or resident has executed an advance directive and whether the patient or resident has a physician to whom he or she normally goes for care; and 4) inquiring of the physician to whom the patient or resident normally goes for care, if known, whether the he or she has executed an advance directive. If a program notifies a family member or designated emergency contact or allows a family member to participate in treatment planning in accordance with this paragraph, the program is not liable to the patient or resident for damages on the grounds that the notification of the family member or emergency contact or the participation of the family member was improper or violated the patient's privacy rights.

In making reasonable efforts to notify a family member or designated emergency contact, the program shall attempt to identify family members or a designated emergency contact by examining the personal effects of the patient or resident and the medical records of the patient or resident in the possession of the program. If the program is unable to notify a family member or designated emergency contact within twenty-four hours after the admission, the program shall notify the county social service agency or local law enforcement agency that the patient or resident has been admitted and the program has been unable to notify a family member or designated emergency contact. The county social service agency and local law enforcement agency shall assist the program in identifying and notifying a family member or designated emergency contact. A county social service agency of local law enforcement agency that assists a program in implementing this subdivision is not liable to the patient or resident for damages on the grounds that the notification of the family member or emergency contact or the participation of the family member was improper or violated the patient's privacy rights.

Treatment Plan

A minor who has been admitted to a residential program as defined in MN Statutes 253C.01 has the right to a written treatment plan that describes in behavioral terms the case problems, the precise goals of the plan, and the procedures that will be utilized to minimize the length of time that the minor requires treatment. The plan shall also state goals for release to a less restrictive program and follow-up treatment measures and services, if appropriate. To the degree possible, the minor resident and his or her parents or guardians shall be involved in the development of the treatment and discharge plan.

The Right to Continuity of Care

Residents shall have the right to be cared for with reasonable regularity and continuity of staff assignments as far as program policy allows.

The Right to Refuse Care

Competent residents shall have the right to refuse treatment based on the information required above. Residents who refuse treatment, medication or dietary restrictions shall be informed of the likely medical or major psychological results of the refusal, with documentation in the individual record. In cases where a resident is incapable of understanding the circumstances but has not been adjudicated incompetent, or when legal requirements limit the right to refuse treatment, the conditions and circumstances shall be fully documented by the attending physician in the resident's medical record.

The Right to Refuse to Participate in Experimental Research

Written, informed consent must be obtained prior to a resident's participation in experimental research. Residents have the right to refuse participation. Both consent and refusal shall be documented in the individual care record.

The Right to Be Free from Abuse

Residents shall be free from mental and physical abuse as defined in the Vulnerable Adults Protection Act (Section 626.557, Subd. 2d). "Abuse" means any act which constitutes assault, sexual exploitation, or criminal sexual conduct as referenced in the Vulnerable Adults Act or the intentional and non-therapeutic infliction of physical pain or injury, or any persistent course of conduct intended to produce mental or emotional distress. Every resident shall also be free from non-therapeutic chemical and physical restraints, except in two possible situations: 1) as authorized in writing after examination by a resident's physician for a specified and limited period of time and only when necessary to protect the resident from self injury or injury to others; or 2) in fully documented emergencies if necessary to protect the resident from himself or others, if the use is authorized by a professional staff member identified in written policies and procedures as having the authority to do so, and the use is reported promptly to the resident's physician by the staff member.

The Right to Treatment Privacy

Residents shall have the right to respectfulness and privacy as it relates to their medical and personal care program. Case discussion, consultation, examination, and treatment are confidential and shall be conducted discreetly. Privacy shall be respected during toileting, bathing, and other activities of personal hygiene, except as needed for resident safety or assistance.

The Right to Confidentiality of Records

Residents shall be assured confidential treatment of their personal and medical records, and may approve or refuse their release to any individual outside the program. Residents shall be notified when personal records are requested by any individual outside the program and may select someone to accompany them when the records or information are the subject of a personal interview. Copies of records and written information from the records shall be made available in accordance with this subdivision and the Minnesota statutes governing access to health records (144.335). This right does not apply to complaint investigations and inspections by the Department of Health, where required by third party contracts, or where otherwise provided by law.

The Right to Know about Services Available

Residents shall be informed, prior to or at the time of admission and during their stay, of services which are included in the program's basic *per diem* or daily room rate and that other services are available at additional charge. Facilities shall make every effort to assist residents in obtaining information regarding whether the Medicare or Medical Assistance program will pay for any or all of the aforementioned services.

The Right to Responsive Service

Residents shall have the right to a prompt and reasonable response to their questions and requests.

The Right to Personal Privacy

Residents shall have the right to every consideration of their privacy, individuality, and cultural identity as related to their social, religious, and psychological well-being. Program staff shall respect the privacy of a resident's room by knocking on the door and seeking consent before entering, except in an emergency or where clearly inadvisable.

The Right to Have Grievances Heard

Residents shall be encouraged and assisted, throughout their stay in a program or their course of treatment, to understand and exercise their rights as residents and citizens. Residents may voice grievance and recommend changes in policies and services to program staff and others of their choice, free from restraint, interference, coercion, discrimination, or reprisal, including threat of discharge. Notice of the grievance procedure of the program or organization, as well as address and telephone numbers for the Office of Health Program Complaints and the area nursing home ombudsman pursuant to the Older Americans Act, section 307(a)(12) shall be posted in a conspicuous place. Every residential program as defined in MN Statues 253C.01, and ever program employing more than two people that provides outpatient mental health services shall have a written internal grievance procedure that, at a minimum, sets forth the process to be followed; specifies time limits, including time limits for program response, provides for the resident to have the assistance of an advocate; requires a written response to written grievances; and provides for a timely decision by an impartial decision maker if the grievance is not otherwise resolved. Compliance by residential programs as defined in MN Statutes 253C.01 with section 144.691 is deemed to be compliance with the requirements for a written internal grievance procedure.

Protection and Advocacy Services

Residents shall have the right of reasonable access at reasonable times to any available rights, protectionists services and advocacy services so that the resident may receive assistance in understanding, exercising, and protecting the rights described in this section and other law. This right shall include the opportunity for private communication between resident and a representative of the rights protection service or advocacy service.

The Right to Communicate Privately

Residents may associate and communicate privately with persons of their choice and enter and, except as provided by the Minnesota Commitment Act, leave the program as they choose. Residents shall have access, at their expense, to writing instruments, stationery, and postage. Personal mail shall be sent without interference and received unopened unless medically or programmatically contraindicated and documented by the physician in the medical record. There shall be access to a telephone where residents can make and receive calls as well as speak privately. Facilities which are unable to provide a private area shall make reasonable arrangement to accommodate the privacy of resident's call. This right is limited where medically inadvisable, as documented by the attending physician in a resident's care record, where programmatically limited by a program abuse prevention plan pursuant to Section 626.557, subd. 14, clause 2, this right shall also be limited accordingly.

The Right to Have and Use Personal Property

Residents may retain and use their personal clothing and possessions as space permits, unless to do so would infringe upon rights of other residents, and unless medically or programmatically contraindicated for documented medical, safety or programmatic reasons. The program must either maintain a central locked depository or provide individual locked storage areas in which residents may store their valuables for safekeeping. The program may, but is not required to, provide compensation for or replacement of lost or stolen items.

The Right Not to Perform Services for the Program:

Residents shall not perform labor or services for the program unless those activities are included for therapeutic purposes and appropriately goal-oriented in their individual medical record.

The Right to Manage Financial Affairs

Competent residents may manage their personal financial affairs, or shall be given at least a quarterly accounting of financial transactions on their behalf if they delegate this responsibility in accordance with the laws of Minnesota to the program for any period of time.

The Right to Associate

Residents may meet with visitors and participate in activities of commercial, religious, political (as defined by the Minnesota statues regarding voting while residing in a community residential program, 203B. l) and community groups without interference at their discretion if the activities do not infringe on the right to privacy of other residents or are not programmatically contraindicated and documented in the resident's record. This includes the right to join with other individuals within and outside the program to work for improvements in long term care.

The Right to an Advisory Council

Residents and their families shall have the right to organize, maintain, and participate in resident advisory and family councils. Each program shall provide assistance and space for meetings. Council meetings shall be afforded privacy, with staff or visitors attending only upon the council's invitation. A staff person shall be designated the responsibility of providing this assistance and responding to written requests which result from council meetings. Resident and family councils shall be encouraged to make recommendations regarding program policies.

The Rights of Married Residents

Residents, if married, shall be assured privacy for visits by their spouses, and if both spouses are residents of the program, they shall be permitted to share a room, unless medically contra-indicated and documented by their physicians in the medical records.

The Rights of Transfers and Discharges

Residents shall not be arbitrarily transferred or discharged. Residents must be notified, in writing, of the proposed discharge or transfer and its justification no later than thirty days before a discharge from the program and seven days before transfer to another room within the program. This notice shall include the resident's right to contest the proposed action, with the address and telephone number of the area nursing home ombudsman pursuant to the Older Americans Act (Section 307(aX12). The resident, informed of this right, may choose to relocate before the notice period ends. The notice period may be shortened in situations outside the program's control, such as determination by utilization review, the accommodation of newly admitted residents, a change in the resident's medical or treatment program, the resident's own or another resident's welfare, or nonpayment for stay unless prohibited by the public program or programs paying for the resident's care, as documented in the medical record. Facilities shall make a reasonable effort to accommodate new residents without disrupting room assignments.

The Right to Know the Rules

Every resident shall be fully informed, prior to or at the time of admission and during the stay at a program, of the rights and responsibilities set forth in this section of all rules governing resident conduct and responsibilities.

Section 2

Disability-Related Laws

Individuals with disabilities and their families are protected under several laws. It's important for individuals with disabilities to understand this and know what laws may apply to them and the rights they have in a particular situation, whether it be work, school, or home. Therefore, examples of laws have been added to this section on rights so you, as a paraprofessional, have a basic understanding of what some of the laws are affecting the rights of individuals with disabilities.

The following are examples of laws that affect individuals with disabilities. This isn't an all-inclusive list, however these are the laws most often referred to in schools and in residential and work settings.

The Americans with Disabilities Act

The most recent law affecting individuals with disabilities is the Americans with Disabilities Act of 1990 (ADA). Read the Fact Sheet from the U.S. Department of Justice and then the article "The Kindness of Others" found in Appendix H to give you a better background of the law and its implications.

Section 504 of the Rehabilitation Act of 1973

The Rights of Individuals with Disabilities Under Federal Law: As part of the Rehabilitation Act of 1973 (Public Law 93-112) Congress enacted Section 504, the first federal civil rights law protecting the rights of individuals with disabilities. Section 504 provides that, "no otherwise qualified handicapped individual in the United States... shall, solely by reason of... handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

This law applies to state and local agencies and governments if they receive any federal money.

This law protects any person with a disability who is "otherwise qualified", just like ADA. That means the person with the disability must be able to perform the necessary tasks (with accommodations and modifications if needed) in spite of the disability. This means, if the disability doesn't prevent the individual from doing an adequate performance on the job, he or she is entitled to the job and cannot, under federal law, be denied the job. For example, a person who is mildly retarded who can pass the drivers license test is entitled to be hired to drive the school van because he or she has proven the ability to perform the necessary tasks in spite of the disability.

Section 504 also applied to school. If a student is in need of accommodations or modifications to learn, he or she is entitled to reasonable accommodations. For example, a person who uses a wheelchair may enroll in a community college and find that the department he or she needs to access doesn't have a ramp or elevator. The school must accommodate that student to access the information. They may do that by relocating the class or lab, or by putting in an elevator or curb cuts. Under Section 504, students who may have learning disabilities are entitled to readers, notetakers, books on tape, or other accommodations to facilitate their learning.

Section 504 came long before ADA but has been recently updated and still covers some situations that ADA may not.

For further information about Section 504 of the Rehabilitation Act, refer to the Fact Sheet provided in the appendices.

Individuals with Disabilities Education Act (IDEA)

IDEA is a federal law (PL 101-476) which was formerly called the Education for All Handicapped Children Act (PL 94-142). There are certain minimum standards all states must comply with under IDEA and then each state can add to that compliance with additional statutes. Minnesota Chapter 3525 and Minnesota Laws on Special Education along with IDEA spell out the rights of parents for their children in special education. Some of these rights include the right to:

- Agree or disagree to the school's request to test the child.
- Have the child given a test that isn't discriminatory based on race or disability once agreement to assessment is given.
- Receive a written copy of the assessment results
- Have assessment results explained thoroughly.
- Have an independent evaluation if parents disagree with the school's assessment. In this case, the school must pay for the evaluation unless, through a due process hearing, the evaluation given by the school is determined to be appropriate.
- Have parents as equal members of the student's planning team that decides if the student needs special education and if so, to what extent.
- Have someone accompany parents to the Individualized Education Plan (IEP) conference.
- Agree or disagree with the action suggested by the school.

Public Law 99-457 (Part H of IDEA)

This federal law requires schools to serve young children with disabilities beginning at birth. The Individual Family Service Plan (IFSP) is the written document, like the IEP, for this law. In this plan, the needs of children are planned from birth to the age of three. Minnesota has developed an IFSP plan. As of the fall of 1993, all services described in the IFSP (by all the agencies involved) must be implemented.

Material on IDEA adapted with permission from PACER Center, Inc., 4826 Chicago Ave. S., Minneapolis, MN 55417, (612) 827-2966

Minnesota Rule 3525.2925: Use of Behavioral Intervention with Pupils

As another example of Minnesota laws that provide rights to individuals with disabilities, the Behavioral Intervention Procedures for Students with Disabilities is included in this section. This law is specifically directed to rules governing the discipline procedures used with students in school who have disabilities.

In 1989, the Minnesota State Board of Education was directed by the Legislature to adopt rules governing the use of aversive and deprivation procedures for students with disabilities. The Board was asked to draft rules which promote the use of positive behavioral interventions, and to ensure that aversive or deprivation procedures, when appropriate for a student, are included in that student's Individual Education Plan (IEP). The rule, which went into effect in January 1992, is intended to encourage the use of positive approaches to modify students' behavior.

Three categories of behavioral interventions are listed in Minnesota's Proposed Permanent Rule for Use of Behavioral Interventions with Pupils Who Have Disabilities. They are *exempted procedures*, *prohibited procedures*, and *regulated procedures*.

Each school district is to revise district policies, where necessary, and to provide any necessary staff development to appropriately implement the new rule. Each district should distribute their written discipline policy during IEP meetings, and review common practices in terms of appropriateness for a particular student.

Exempted Procedures

Exempted procedures are planned instructional techniques which are common practices in schools, and consistent with the school discipline policy. Exempted procedures may include, but are not limited to:

- The use of corrective feedback;
- The use of physical assistance to facilitate the completion of a response (such as guiding a child's hand to teach a handwriting skill where there is no resistance);
- Requesting that a student leave an activity for a brief period of time, or the temporary delay or withdrawal of goods, services, or activities as a consequence of their inappropriate use.

Exempted procedures would appear on an IEP when they are used as instructional techniques to help a child meet IEP goals and objectives.

Prohibited Procedures

Prohibited procedures are those procedures which, under Minnesota law, have been declared illegal for use in schools with children who have disabilities. Such procedures are never to be used by teachers or other school staff. Since they are expressly prohibited, they would never appear on a student's IEP.

The following procedures are prohibited in Minnesota for use with students who have disabilities:

- Corporal punishment;
- Requiring students to stand or sit in a position causing physical pain, the use of intense sounds, lights or other sensory stimuli as an aversive stimulus;
- The use of noxious smell, taste, substance or spray as an aversive stimulus;
- Denying or restricting a student's access to equipment such as hearing aids and communication boards;
- Faradic skin shock;
- Totally or partially restricting either of a pupil's auditory or visual senses; *or*
- Withholding regularly scheduled meals or water.

Regulated Procedures

Regulated procedures are any interventions used in a planned manner that meet the definition of an aversive or deprivation procedure (see *Definitions* on the last page of this section). Regulated procedures may be permitted as instructional strategies only when positive or less intrusive methods of encouraging behavior change have been tried without success. Any regulated procedure that is being considered must be clearly articulated in a Behavioral Intervention Plan (BIP), as part of a student's IEP, and can be implemented only with the signed consent of the parents or in an emergency situation. Regulated procedures include:

- The use of manual restraints
- The use of mechanical or locked restraints (e.g., handcuffs)
- The planned use of suspension or dismissal from school
- The use of time-out (where the student is removed from the educational program and may be placed in an isolation room or similar space), *or*
- The temporary delay of regularly scheduled meals or water not to exceed thirty minutes (except in an emergency).

If a regulated procedure is being considered for use with a student who receives special education services, a professional with expertise in the use of positive approaches to behavior management must be a member of the IEP team.

Assessment

An assessment must be performed before any regulated behavioral interventions are recommended or initiated. The assessment must examine the purpose of the intervention, the effect of the behavior exhibited by the student, and its seriousness. The assessment summary must describe:

- The behavior for which a regulated procedure is recommended;
- A base-line measurement of the behavior;
- Documentation of two positive behavioral interventions, and any extra interventions attempted and their effectiveness;
- A review of frequent use of *Exempted Procedures* (e.g., sitting in the hallway or being sent to the principal's office);
- Documentation that other treatable causes for the behavior have been ruled out (health, medical, etc.);
- What alternative procedures have been considered and ruled out and why, *and*
- A description of the proposed regulated procedure.

Positive Behavioral Interventions

Before any regulated behavioral intervention can become a part of the IEP, the school must: 1) document that it has tried and was unsuccessful with positive approaches to manage the offending behavior, and 2) show that the purpose of the intervention is to enable the student to develop appropriate skills. (The use of Regulated Procedures should not be considered just to eliminate unwanted behaviors, or for the convenience of staff).

If the two positive behavioral interventions have not been successful in meeting the IEP goal a team meeting must be convened to review the student's IEP. If the IEP team decides that the use of a regulated procedure is necessary to meet the goal, the procedure must be written into a Behavioral Intervention Plan in the IEP. The BIP must list:

- The target behavior and a base-line measurement of its frequency and severity;
- A description of the proposed behavioral intervention procedure;
- The conditions under which the procedure will be used;
- An explanation of why the procedure was chosen;
- A statement of the expected behavior change that will occur;
- A description of any discomfort, risk, or side effects;
- The conditions or circumstances under which the intervention can or must be discontinued prior to team review;
- The anticipated effects if the procedure isn't used;
- Who will implement the program;
- The team review and evaluation date, not to exceed two months;
- Coordination with home or care facility, *and*
- The parent's informed consent (which may be withdrawn at any time by notifying the program administrator; the procedure must be stopped immediately upon parental request).

Parental Consent

Parents must be contacted within three days of their having withdrawn consent to the Behavioral Intervention Plan in the IEP, to determine the need to review and amend the Behavioral Intervention Plan and the need to convene an IEP meeting for a change in placement or program. If parents are divorced but have joint legal custody, informed consent must be obtained from both parents before using a regulated procedure.

Emergencies

In the case of emergencies, regulated procedures may be used to protect a student or other person from injury, emotional abuse, or to prevent severe property damage, even if those procedures are not written into the IEP however, emergency procedures that are used twice or more per month require that a team meeting be called to see if the IEP continues to meet the needs of the child.

Any time a regulated procedure is used in an emergency (any time that the use of the procedure hasn't been planned in the IEP), district administration and parents must be notified immediately.

Time-out

One of the most frequently used regulated procedures is time-out. Exclusion time-out occurs when a child is removed from his or her regularly scheduled educational program. Seclusion time-out is when a child is placed in a specially designed isolation room. The use of time-out must be addressed in a Behavioral Intervention Plan as part of a child's IEP. Included in the BIP must be a provision for continuous monitoring of the child during time-out, the criteria for the child's return to his regular activities, access to water and restrooms if time-out exceeds fifteen minutes, and documentation of the number of occurrences of time-out and the length of time for each time-out. Time-out rooms must be safe for children, with walls and floors covered to guard against injury. Light switches must be outside the room. A time-out room must have an observation window for continuous monitoring, have smoke and fire monitoring devices, be well lit, clean, heated, and ventilated, and must measure at least five by five feet.

Independent Review Committee

An Independent Review Committee must be available in each district as an option for either parents or school staff, to review the Behavioral Intervention Plan (BIP). The team must contain at least two members who aren't employees of the district. Parents may appoint one member of the team if they desire. Districts must inform parents of their right to request a review; the responsibility of the committee is to review relevant assessment and make recommendations regarding the Behavioral Intervention Plan. The decision of the Independent Review Committee is advisory only and has no power to override the decision of the IEP team; it should be viewed as a "second opinion" when either the parent or the school has concerns regarding the planned interventions for a particular child. The committee must include persons who are knowledgeable about cultural and ethnic issues as well as about behavioral interventions.

Definitions

- **Aversive stimulus:** an object used or an event or situation occurring immediately after a specified behavior in order to stop the behavior (a consequence perceived as unpleasant).
- **Aversive procedure:** the planned application of an aversive stimulus (the planned use of consequences).
- **Deprivation procedure:** the planned delay or withdrawal of goods, services, or activities the child would otherwise receive if an identified behavior occurs or in an emergency situation.
- **Time-out:** a procedure in which a student is completely removed from the educational activity. Seclusion time-out occurs when a student is placed in a specially designed isolation room or similar space.
- **Emergency:** a situation in which immediate intervention is necessary to protect a student or others from physical injury, or to prevent severe property damage.

Provided by PACER Center, Inc., 4826 Chicago Ave. S., Minneapolis, MN 55417, (612) 827-2966. Refer additional questions you may have to PACER Center.

Summary

Knowing your rights and how to use them in specific situations is a key point in the self-advocacy process. It's also beneficial to know where to get new or additional information about rights and laws. This chapter discussed specific rights and laws specific to individuals with disabilities.

Questions to Ponder

- What are three of your individual rights? How did you learn about these rights? How do you learn about the rights of individuals with disabilities?
- How do you feel when your rights are being violated?
- As a paraprofessional, what do you do to assure the rights of an individual with whom you're working aren't being violated?

5

Chapter Five

Making a Commitment to Self-Advocacy

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Introduction

In this section you will read about ideas you can use to promote self-advocacy with individuals you work with. Think of what you do or will do on a daily basis as a paraprofessional. Compare what you do with the sections below: how do you compare? What can you do to improve your promotion of self-advocacy?

Upon completing this chapter, you should be able to:

- Describe ways you and others can encourage and promote self-advocacy for individuals with disabilities.
- Describe ways the community can encourage self-advocacy for individuals with disabilities.

Section 1

Promoting Self-Advocacy in Individuals with Whom You Work

Read the following tips: they can be used as ways for you to promote and encourage independence, empowerment, and self-advocacy in your setting.

Tips for Encouraging Self-Advocacy

- Make a commitment to yourself, that promoting self-advocacy is crucial to the future success of the individual.
- Create a positive environment in whatever setting you're with the individual.
- Involve the administration in your efforts to encourage self-advocacy.
- Promote self-advocacy as a philosophy that will encourage independence.
- Involve individuals with disabilities as a group to work toward their own advocacy.
- Prove to other "non-believers" that providing opportunities for people to advocate for themselves is the best guarantee for their success. Share stories highlighting self-advocacy at work.
- Ensure that goals for the development of empowerment and self-advocacy are part of the team process and the individual planning process.

What Works to Help People Advocate for Themselves?

People (parents, relatives, friends, and staff people) need to see and treat the individual as a responsible person. Some ways to promote that are:

- Firmly believe the individual has the right to choices, both in everyday life and setting life goals.
- Don't label the person, but get to know him or her as an individual.
- Ask and listen with care to what the person wants, what the person's goals are, and what specific help the individual needs. Do not assume you know what he or she needs.
- Focus on the individual's capabilities rather than his or her inabilities.
- Match support to the individual instead of fitting the person to what support is available.
- Encourage the individual to work on what he or she wants to work on, even if it's hard to see how far the person can go toward the goal.
- Work with the individual to find ways to make what the individual wants possible by helping to problem solve and to connect the individual with people who can help and be trusted.
- Realize that some of the most valuable learning comes from mistakes. The individual has as much right to make mistakes as anyone else.
- Avoid using labels. When labels are used, expectations are diminished. People do not expect someone with "that label" to be able to speak for themselves to make their own choices, or to be heard.
- Encourage individuals to participate in integrated neighborhood activities. Individuals with disabilities need to be seen as active members in the community who have a valuable contribution to make. When this happens, the old segregation stereotypes can be eliminated.

"What Works to Help People Advocate for Themselves?" is adapted from *Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves*, Report #90-4, October 1990, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

Promoting Self-Advocacy

What does this mean for you as a paraprofessional working with individuals with disabilities? How can you promote self-advocacy with the individuals with whom you work and still support them in ways they need? How are you supposed to know when you're giving too much support and when you aren't giving enough? Make a list of ways you can promote self-advocacy of individuals with whom you work. Bring it to class to discuss with the group.

- In the classroom, I can promote self-advocacy by:

  ____
  ____
  ____
  ____

- In the community, I can promote self-advocacy by:

  ____
  ____
  ____
  ____

- On the job with individuals, I can promote self-advocacy by:

  ____
  ____
  ____
  ____

- In the neighborhood, I can promote self-advocacy by:

  ____
  ____
  ____
  ____

- Within the family, I can promote self-advocacy by:

  ____
  ____
  ____
  ____

- Within myself, I can promote self-advocacy by:

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  ____
  ____
  ____

What Can Be Done To Strengthen the Commitment to Self-Advocacy?

Read the following action steps you can take with individuals and their families to improve their lives and their ability to promote self-advocacy. What other steps would you suggest for your community? Write them down in the space provided.

Encourage individuals with disabilities (and their families) to:

- Speak for themselves by becoming politically active
- Involve community leaders in their lives and their issues
- Influence the way the media presents people with disabilities
- Participate in disability service boards, councils, task forces, etc.
- Reach out into the community for help

Teach individuals with disabilities (and their families) how to:

- Become informed about government action and laws related to disabilities.
- Work on committees for local, regional, and national reform
- Bring community leaders into the issues of individuals and their families.
- Watch the way people with disabilities are shown in advertising, on television, and in movies. If it isn't accurate, write and call companies to educate and make them aware.
- Read how individuals with disabilities are reported, described in the newspaper, magazines, etc. If it isn't accurate, write and call to educate and make others aware.
- Find out what committees and task forces are doing in behalf of individuals with disabilities in the community.
- Think about their relationship with service providers. Are they addressing the issues. Are they serving the needs? If not, work to change this.
- Find out what others are doing nationally to create change and promote advocacy.
- *Other steps:*

Adapted from *Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves, Report #90-4*, October 1990, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

Summary

As a paraprofessional, you can make a commitment to promote the self-advocacy of individuals with whom you work. This chapter discussed specific tips like creating a positive environment, promoting the self-advocacy philosophy, ensuring empowerment goals, and sharing stories. Also discussed were ideas of how others and the community could promote and make a commitment to self-advocacy for individuals with disabilities. Some tips included not labelling people, listening, making no assumptions about people, and participating in inclusion activities.

Questions to Ponder

- What personal commitment will you make to promote self-advocacy in the individuals with whom you work?
- Have you seen families promote self-advocacy for a family member who has a disability?
- How have you seen communities promote self-advocacy for people with disabilities?
- What do you feel is the most important thing you could teach individuals and their families about self-advocacy?

6

Chapter Six

Facilitating Friendships & Socialization Skills

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Introduction

Individuals with disabilities who have traditionally been served in segregated settings are now becoming full members of society – in the classroom, in the workplace, in the neighborhood. But physical integration doesn't automatically lead to social integration. The physical presence of persons with disabilities in all settings isn't, in itself, enough. Even though formal integration has often taken place, individuals with disabilities are still quite isolated in the environment:

Individuals with disabilities need the skills to acclimate to the environment, make friends, and develop long-lasting relationships. That's why it's important for someone in the individual's life to have the skills to facilitate the development of friendships. This module is designed to give background and practical suggestions to paraprofessionals to assist individuals in these efforts.

Upon completing this chapter, you should be able to:

- Identify the philosophy in facilitating friendships for individuals with disabilities.
- Describe the three kinds of activities that help people build connections with others: finding opportunities, interpretation, and accommodations.

Section 1

Facilitating Friendships and Socialization

It may seem artificial to say we need to facilitate friendships, that friendship should be something that just happens. But relationships between any two people don't just happen. They take work. And teaching individuals with disabilities how that "work" happens is very important.

Positive relationships and friendships are important to everyone. It enhances learning, creates a sense of belonging, fosters necessary interdependence, and (especially for individuals with disabilities) helps create a feeling of, "I'm like everyone else. I'm not different. I'm accepted."

No one person can be the sole source for facilitating friendships. All the people who work with the individual need to know his or her needs and desires to establish and help explore opportunities and strategies for facilitating friendships. Ultimately, the best facilitator is the individual him- or herself. Helping the individual attain the skills to facilitate personal friendships successfully is the ultimate goal.

Friendships can't be forced on people. Because you as a paraprofessional often work individually or in small groups with people, you can facilitate relationships and foster them between individuals in their natural daily environment.

Check Your Friendship Quotient

Mark whether you think the following statements are truth or myth. There are no wrong answers. Write any reaction you have next to the statements. This will facilitate group discussion.

☐ ☐ ☐ 1 The enabling of people with disabilities is important to help them make friends and self-advocate.

☐ ☐ ☐ 2 Government funding trends indicate that creating jobs is of greater importance than creating relationships.

☐ ☐ ☐ 3 Paraprofessionals are in key positions to facilitate friendships between individuals in natural settings (work, school, recreational activities).

☐ ☐ ☐ 4 With all the responsibilities and needs of individuals, it's hard to find time to observe ways to facilitate friendships.

☐ ☐ ☐ 5 Most assessments focus on a person's academic deficits rather than on personal aspirations and requests.

☐ ☐ ☐ 6 The "service" system keeps individuals with disabilities on the receiving end of relationships where they're not expected to contribute and therefore have little opportunity to learn how to establish personal relationships.

☐ ☐ ☐ 7 Most individuals with disabilities don't have many real opportunities to establish friendships.

☐ ☐ ☐ 8 Part of the reason people with disabilities don't often find and establish long-lasting relationships is because of the attitudes of society about persons with disabilities.

☐ ☐ ☐ 9 If people with disabilities are not well integrated into society, their chance for establishing friendships with persons without disabilities is slim.

☐ ☐ ☐ 10 When encouraging independence and facilitating friendships, the focus should be on diminishing and fading support.

☐ ☐ ☐ 11 People with disabilities never totally blend in because subtle social rules and cues are impossible to teach.

☐ ☐ ☐ 12 Self-advocates are happier working, living, and socializing with people like themselves.

Adapted from *Using Natural Supports in Community Integration* (1990) by E. Curtis, M. Dezelsky, and C. Coffey, Salt Lake City, Utah: New Hats, Inc.

Activities and Building Connections

According to Zana Lutfiyya (1988), friendship facilitation is defined as "providing opportunities where people can comfortably come together to meet each other." Facilitation means that someone (in this case, maybe the paraprofessional) is taking the lead or the key responsibility to ensure that individuals are making the necessary connections with peers that may develop into friendships. Facilitation is an unobtrusive process which taps the expertise of those who know the individual and are willing to help the process along. When needed, the facilitator should talk through the problems in relationship building and be there to help foster and nurture the friendship development. And, just like in self-advocacy, the facilitator also needs to know to back out and allow the individual to foster and nurture the friendship on his or her own.

Lutfiyya identifies three kinds of activities that help people build connections with others: *finding opportunities, interpretation,* and *accommodation.*

- **Finding Opportunities:** This means actually setting up activities, events, or situations that can bring people together. In order to do this, one has to know the individuals involved, their interests, and try to create or find situations and activities around similar interests.
- **Interpretation:** This means helping the individual with the disability present him- or herself in a positive way to others. The individual needs to learn how to present him- or herself based on strengths, common interests, assets, and positive human qualities. In this way, individuals with and without disabilities can look to each other for friendship based on their common attributes (and not be turned away by each others' differences).
- **Accommodation:** This means making necessary changes in the environment so the individual with a disability can interact with others in the best possible way. It means helping to facilitate an environment that feels comfortable for all to interact with each other without feeling awkward.

Adapted from *Reflections on Relationships Between People with Disabilities and Typical People* by Z.M. Lutfiyya, Syracuse University, The Center on Human Policy, Syracuse, NY, 1988.

Group Exercise: Facilitating Friendships

The following three situations are examples in which paraprofessionals can facilitate friendships. Read each situation and then break into small groups to discuss these. As a group, determine the opportunities, interpretations, and accommodations. Be prepared to share your group's answers with the entire class.

Situation 1

Carol is a paraprofessional in a classroom for students with significant behavior support needs in an elementary school (grades 1–5). She and the supervising teacher have been working all year with Fred, who's ten years old. Fred usually ends up in their "time out" area whenever he's required to work in small groups on writing assignments in the regular classroom. He acts out against other children. There's one friend in the class, José, who usually brings Fred down to time out, but other than that they have little to do with each other. Carol learns that Fred and José live in the same neighborhood, ride the same bus, and go to the same church, but have never really gotten to know each other. They rarely interact unless the teacher asks José to bring Fred to time out. When asking Fred about José, he speaks of him as a close friend. Carol feels there is potential here to develop this relationship. What steps can Carol take with Fred and José using the three steps: finding opportunity, interpretation, and accommodation?

- Finding opportunities:

- Interpretation:

- Accommodations:

Situation 2

Lisa works at a family-style restaurant. She's been there for nine months. Her job coach and the restaurant trainer are very pleased with her work. She is polite to customers. Many of the customers know Lisa because they all live in the neighborhood. When they start a conversation with Lisa she's nice, but doesn't make real "contact" with them. She says she likes her job. When Bob, the job coach, asked her if she was making friends on the job, she looked at him and said, "I didn't know I was supposed to." There are other young women Lisa's age that work at the restaurant with her. Bob learned they've tried to be friendly to Lisa and ask her to do activities with them, but they say she is so "shy" she always says no. What can Bob do to facilitate friendships on the job for Lisa?

- Finding opportunities:

- Interpretation:

- Accommodations:

Situation 3

Andy lives in a group home in an established neighborhood in a large city. He rides the bus daily to his job at a nearby printing shop where he separates garbage and recyclable materials and other odd jobs. He sees the same people at work each day, the same people on the bus, the same people when he's out in the neighborhood, and the same residents and staff people in his group home. Andy expressed to Alice, a group home paraprofessional, that he felt lonely. He related all the people in his life he comes in contact with every day (as stated above) but he says he has no real friends and he feels sad. What can Alice do to facilitate friendships for Andy?

- Finding opportunities:

- Interpretation:

- Accommodations:

Summary

This chapter gave background information and practical suggestions for paraprofessionals to assist individuals with disabilities acclimate to the environment, make friends, and develop long-lasting relationships. By filling out the "Friendship Quotient" checklist, you were able to gain a better understanding of your feelings as they relate to facilitating friendships.

Questions to Ponder

- How do you make friends and develop long-lasting relationships?
- How can you support the individuals with whom you work to attain the skills to make friends and develop long-lasting relationships?

Chapter Seven

7

Issues in Developing Friendships for Individuals with Disabilities

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Introduction

There are many issues relating to the development of friendships for individuals with disabilities. This chapter discusses a number of them, including understanding the importance of community ties; developing friendships, acquaintances, and membership in the community; keeping in touch; being a part of a family; having a partner; and being a good neighbor.

Upon completing this chapter, you should be able to:

- Understand the importance of community ties and friendships.
- Understand issues surrounding developing and sustaining acquaintances, friendships, interests, and membership in the community.
- Understand issues surrounding being part of a family, having a partner, or being a good neighbor.

Section 1

The Importance of Community Ties and Friendships

The importance of community and the sense of belonging for all people can't be underestimated. Many people with disabilities often have missed the typical opportunities throughout their lives to meet and develop friendships naturally. They have lived a life more dependent upon others than people without disabilities. This makes it more difficult to establish natural friendships and ties. It's so important for persons working and living with individuals with disabilities to realize the need for connections and ties and help facilitate that in any way possible. It's the connection that we feel with others that gives our lives meaning. Some of those connections may be strong, others may be weak. Some of those connections come from work, school, church, the neighborhood, and some come from close friends and family. Each type of connection or tie has importance and meaning. Critical elements that determine the strength of connections or ties to someone may be:

- **Time:** The amount of time spent with someone helps to determine the strength of the relationship. If you're a paraprofessional working one to one with a person who has medical needs, you may spend eight hours closely working with him or her daily. Without realizing it, you may be the most important person in the individual's life by virtue of the time you spend together. This means you can have a tremendous impact on modeling relationship behavior with him or her.

- **Intensity:** The amount of emotion attached to the relationship with an individual equals the intensity of that relationship. If there's a great deal of emotion in a relationship, there will be more intensity in those ties than in other relationships where there's less emotional attachment. If a paraprofessional has worked with the same supervisor for many years, has gone through many family issues together and many challenging students or individuals and many work related changes together, the ties to that supervisor are probably very strong because much emotion is attached to the relationship. If a new paraprofessional comes on staff with this team, his or her ties (in the beginning) will be weak, with little emotion involved.
- **Intimacy:** The amount of trust and confidence that is shared with individuals determines the level of intimacy. Two co-workers who have shared many work and family experiences together over the years and have shared their fears, hopes and dreams, have developed a level of intimacy with each other. Co-workers who happen to ride the same bus or each lunch in the cafeteria at the same time, but interact seldom, have a much weaker tie and don't share a level of intimacy.
- **Reciprocity:** Part of creating strong ties is in the exchange people have with each other. That exchange may be services between each other such as sharing equipment, or giving help to someone on the job, or it may be sharing living space. All relationships (either weak ties or strong ties) require some give and take. The level of give and take involved partly determines the strength of the tie between people. If neighbors share buying and using lawn equipment they have closer ties than people who simply greet each other when entering an elevator. Both are example of reciprocity, at different levels.

There are many important connection sources for all people. These are also essential for individuals with disabilities as a means for developing relationships. Some sources include friendships, acquaintances, memberships in clubs and organizations, keeping in touch with others, being part of a family, having a partner, being a neighbor and knowing neighbors. Although each of these areas has the potential for developing relationships, for individuals with disabilities, there can also be particular challenges. Knowing and understanding these challenges can help prepare you, as a paraprofessional, to better facilitate friendships. The following sections will look at each of these "sources of ties" in terms of what the difficulties may be for individuals with disabilities. Each section will then address some ways that staff can help alleviate these difficulties.

Section 2

Issues in Developing Friendships

Living at home with parents or in large group homes, many people with disabilities find themselves with very limited opportunities to make friends. They may find themselves tied pretty closely to their parents' social lives, surrounded mainly by people of an older generation, or by company only of their parents' choice. Or they may find that "services" put limits around with whom and where they meet people. For instance, the size of the building or the way it looks may make it harder for people to mix naturally. When large numbers are grouped together, it's easy for segregated group arrangements to prevail.

Attempts to provide volunteers or befrienders can be very helpful, particularly when they mean that one helpful citizen is matched up with one person with a disability. The one-to-one matching often doesn't happen and volunteers work with whole groups. In such cases, it isn't clear what roles the volunteers play or how they differ from staff.

Some services are so arranged that almost every part of life happens under one roof or on one site – living arrangements, daytime activities, leisure and recreation. This means that most people with disabilities meet relatively few people who are not either other people with disabilities or staff who are paid to be with them. Even these staff members move in and out of people's lives. When these well known staff people leave, there's no one left who knows the individuals with disabilities well enough to be able to sustain past friendships. Because of limited opportunities for making friends, many people with disabilities find themselves with few friendships in the first place. Meeting people and making friends leads to the second important process – sustaining friendship – doing all those things which help keep friendships alive. Strong relationships can survive many challenges, but if the friendships must be sustained through long separation, distance, and lack of communication, it probably won't survive.

Friendship – What Helps Keep It Alive?

Of all the different ways of being connected with others, friendship is probably the most important. The essence of friendship is that it's freely given and that makes it particularly difficult to "arrange". These ideas could help you facilitate for those you serve:

- Evaluate the individual's present circle of relationships by exploring these questions with him or her:

  - What have the individual's life experiences been?
  - Who are the people in the individual's life?
  - What kind of roles does the individual play in those relationships?
  - Where does the individual spend time?
  - In what activities does the individual participate?
  - What works and what doesn't work for this individual?
  - What are the individual's interests, gifts, abilities?
  - What does the individual have to contribute to others?
  - What help does the individual need?
- Pay particular attention to recognizing friendships, especially when the individual him- or herself may not be able to tell you much about it directly.
- Don't disrupt friendships by doing things such as transferring people a long way away, or moving them from school to school (or house to house), or shifting staff who are just getting acquainted with individuals.
- When someone does have to move and an important relationship is under threat, take extra care to find ways of maintaining that relationship and seeing that other opportunities are created.
- Ensure that people with disabilities have lots of positive encouragement and active support for developing connections with people thereby increasing the chances that acquaintances may grow into friendship.
- Other suggestions that work:

Section 3

Issues in Developing Acquaintances

Many acquaintances grow out of everyday life experiences and are a fairly natural part of the business of living in a family, a neighborhood, and going to school or work. When people with disabilities have these activities in their lives, they are more likely to develop acquaintances in natural settings. Too often people with disabilities don't have these opportunities. What they often have instead is a series of organized activities that are structured by families, teachers, or service providers. Individuals make acquaintances, but often their closest acquaintances are with you, as paraprofessionals or other service providers. The natural act of developing acquaintances is not natural or easily available.

Acquaintances seem to be sustained by simple acts like getting together for a cup of coffee, going to a movie together, or saying "hi" while walking along the street. Simple acts of hospitality – buying a round of drinks, making a cup of tea – are all the stuff of acquaintanceship. With time, some people unused to these skills are able to learn them. Others will always need someone on hand to ensure these customs and common social skills are observed, and that the person with a disability gets to participate, even if he or she may not be skilled in initiating them or carrying them through on their own.

The lack of a rich circle of acquaintances and sensitive help which could develop and sustain it means that many people with disabilities simply lack company a lot of the time. They may spend a lot of time with other people but have no sense of connection to them. Perhaps even more important, individuals with disabilities may lack some of the vital kinds of useful contacts which acquaintances bring into the lives of everyone.

Acquaintances – What Helps Create Them?

Since forming and sustaining an acquaintance doesn't demand too much of the people involved, it's relatively easy to foster. Some ways of helping are:

- Use places where other people are, and at times when other are there. Go to a local cafe or local park where others of the same age may frequent.
- Establish a routine of using places such as the a swimming pool or library, so that you're likely to run into the same local people often.
- Always be careful to set an example of appropriate social behavior. For example, set an example of appropriate noise level in public places by speaking at the appropriate volume.
- As a paraprofessional, you can act as a bridge builder to help facilitate acquaintances when you're out in the community with individuals. You'll also be modeling behavior on how to introduce one's self to others.
- Other suggestions that work:

Section 4

Issues in Developing Membership

Many people with disabilities don't belong to any organizations, groups, or classes – others belong only to those specifically for people with disabilities. Often from the time they are young children, individuals spend time in "special" organizations with others who are labeled in the same way.

In segregated schools and clubs, their experience of life becomes more and more separate from others of the same age and their activities child-oriented and without any valued responsibility. As people with disabilities spend more and more time with each other they feel less comfortable with people without disabilities, and people without disabilities feel less comfortable with them. In the end everyone begins to feel that they just don't fit in and are "better off with their own kind". A vicious circle is created. For these reasons, many people with disabilities need some help or support to enable them to join and actively participate in ordinary groups and classes.

People with disabilities need people who are not staff and not paid to be with them to sponsor and support their participation and membership in organized groups- people with the same interests as themselves.

Membership – What Helps Get it Started?

Becoming a member of an organization can help build a sense of belonging. Here are some ideas to help determine what's available, appropriate, and of interest in a particular area. These ideas can help you help someone you work with become connected to an organization.

- Making and updating a complete list of all the groups, organizations, and clubs you can think of. Brainstorm at staff meetings about additional ideas. Make a map of where these are located in your area. Give the list to parents and other staff.
- Help the individual develop the skills he or she may need to join a group that is of interest.
- Include discussions about membership in groups as part of the individual planning meeting with the team.
- Accompany the individual to several meetings that he or she is interested in until there's a comfort level for independence.
- Find someone who has an interest in the activity, class, or cause and who will accompany the individual to the meetings.

- Other suggestions that work:

Section 5

Issues in "Keeping in Touch"

Many individuals with disabilities have no basis for developing interests because they have been severely deprived of resources, relationships, and experiences. Many don't know what to be interested in because they haven't been introduced to interests. Others may have clear interests but have had few opportunities to develop them. There are also people who have had interests selected for them by staff or parents, or have become locked into interests which they once had – such as children's games or adolescent records – that they have had no opportunity to replace with more appropriate adult ones.

Other people's expectations can be a problem. One parent said, "My daughter basically isn't interested in doing anything – nobody wants to spend time with a person like that. She's happy enough with other people like herself. Trying to draw her out into the kind of social life we lead wouldn't work: in fact, it would be really unkind." The problem is not only to get beyond these very negative assumptions, but also to get beyond the very real power that parents and staff and others may exercise over the choices people with disabilities can make in general.

Social worlds provide easily accessible ways of gaining a place in community life. The potential choices are almost unlimited. What stands in the way for most people with disabilities is the lack of someone to provide the "way in", and give long-term support for participation and involvement – keeping up the subscriptions, organizing the collection, attending events. Support is critical.

Keeping in Touch – What Helps?

Once relationships have been formed, it's hard to sustain them and keep them going. This is hard work. Here are some ideas to help the process.

- Talk with the individual about him- or herself. Have him or her tell you or show you what they are interested in. Think of connections these interests can make to developing relationships within your community.

- Introduce the individual to a wide variety of opportunities and activities. Get the individual to try different types of activities.
- Find people who are willing to give continued support to the individual's interest in an activity. Are there friendships that can develop out of this?
- Take time to find out what is available in your community so that you can be a resource to individuals when they show an interest in becoming involved. Be ready with ideas.
- Other suggestions that work:

Section 6

Issues in Being Part of a Family

Many children and adults with disabilities live with their parents throughout their entire lives. The family takes on a lifestyle that is not always typical, due to the particular needs of the individual. There are other individuals with disabilities who live away from their families. They sometimes have difficulty maintaining good contact with their families. This creates problems for both the individual and the other family members. In order to feel connected to the family, whether living with them or not, some active connections may need to take place.

Being Part of a Family – What Helps?

The point is not just to have a family but rather to have an active connection with family. You can help and support this connection when you:

- Ensure that administrative arrangements (like the rules and regulations in a residential setting) don't become obstacles to an active connection with family. Make sure connection and involvement by family is encouraged.
- Help the individual know his or her family history (where the family members are and where they are from) to develop a sense of connection and belonging to the family.
- Arrange for family members to share photos of various family members and have the individual share these with others, explaining who they are and their connection to themselves.
- Help individuals celebrate the traditional and special times

when families are together: Christmas, Passover, weddings, funerals, birthdays, and other times specific to the individual's cultural background.

- Support individuals in having a growing and developing relationship with their family, and at the same time respect and support the individual's need for independence.
- Make sure the individual's needs are being met, even if that means not including the family.
- Other suggestions that work:

Section 7

Issues in Having a Partner

Many people with disabilities, whether they lived with their family growing up, in institutions, or in the community, are now forming partnerships and/or marrying. This situation sometimes creates considerable concern among parents, staff, and people who plan and manage services. They are not always as helpful as they might be. One reason why it seems so challenging when people with disabilities form partnerships is that it shatters old powerful myths like "these are children that never grow up and therefore have no sexual urges". Many people have a hard enough time talking about these issues in their own lives and would rather ignore than support the union of people with disabilities. Individuals with disabilities need a lot of support in developing partnerships.

Supporting Partnerships: What Can You Do to Help?

The need for a partner has to be understood in the context of a wider need of satisfying friendships. When people have very few friends at all they may find it very hard to choose a partner. What you can do to help:

- Some special skills may be helpful (e.g., counseling, therapy, etc.) in supporting people who are making decisions about important relationships. Probably the most helpful resource though is a wide range of other close friends. Help to facilitate obtaining counseling and discussions with other friends if this seems appropriate.
- People who have many close friends with many different kinds of interests and resources are more likely to be able to make

some longer-term commitments to one person.

- When people find it very hard to communicate, it's important to try to understand what kind of a partnership they may be seeking. They may not be making typical choices that others make. Individuals in these situations may need someone to help them decide what kind of relationship would work out best for them. If you, as a paraprofessional, have spent a lot of time with the individual, you probably can offer a good listening ear and support as they work through to the best choice.
- Other suggestions that work:

Section 8

Issues in Being a Good Neighbor

Neighbors are people who live near each other. In a big city that might mean the people on your block. In a small town it might mean a much larger area. Good neighbors are friendly and helpful. They should respect one another's privacy. Privacy means not intruding in the other person's life. It means respecting confidences. *Friendliness* means offering warm, polite greetings, and generally being interested and encouraging. *Helpfulness* means doing favors for others like keeping an eye on someone's house if they were away, or helping someone with a yard project. It also means being helpful in emergencies. Sometimes a casual relationship between neighbors can become a real friendship over time. When a person with a disability who needs assistance with certain projects lives in a neighborhood, it's nice to have neighbors to turn to that will be helpful to him or her. People with disabilities often don't have this close, healthy relationship with neighbors and don't understand how these relationships work. As a paraprofessional, you can set a good example of how a person acts "neighborly" and encourage individuals to develop those kinds of attitudes and supports in the neighborhood in which they live.

Supporting Neighborhood Relationships: What Can You Do to Help?

Establishing neighborhood relationships may take some support from you. Here are some ideas to help support those types of relationships.

- Be helpful and considerate so as to serve as a good role model for how good neighbors act toward each other.
- Encourage individuals to exchange greetings with their neighbors.
- Don't act as if you must "ask permission" when people with disabilities move into a neighborhood, but instead, first make sure that good ground work is done in the neighborhood for healthy relationships to take place.
- Teach individuals that it's all right to ask neighbors to help in small ways – to lend their garden shears, or give advice on trimming the hedges. Suggest that the individual offer to water the yard for an elderly neighbor. This is good advice for a way to start a relationship.
- Other suggestions that work:

Adapted with permission from *Ties and Connections: An ordinary community life for people with learning difficulties* (1988), Roger Blunden, The King's Fund Centre.

Summary

This chapter examined issues in developing and sustaining friendships for individuals with disabilities. Specific suggestions were offered of ways that paraprofessionals can support the growth of friendships for people with whom they work. You were also given an opportunity to explore your feelings about friendships for people with disabilities. Building on what came in this chapter, Chapter Eight will discuss ways of developing social networks.

Questions to Ponder

- How do you define a friendship?
- How can you be a "bridge builder" for an individual with disabilities with whom you work? Who would you identify as a non-staff "bridge builder"?
- Consider your role as a neighbor. Does it differ from your perceptions of "neighbor" you had when growing up?
- Do you know the organizations and groups in the community? If not, how can you find out about them?

8

Chapter Eight

Developing Social Networks

81 Introduction
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Introduction

A social network is all the people with whom an individual does activities or all the people who are important to the individual. The social network includes all the people the individual comes in contact with – such as the bus driver, co-workers, schoolmates, parents, and friends. Some contacts are frequent and some are infrequent, but they're all significant and a part of one's social network. The following quote illustrates the importance of your helping to develop an individual's network of support:

> "One candle alone has the power to give light, and we empower one another by passing the flame. If we give our gift or flame to another, our flame will not be diminished, but there will be more light. The circle of support helps us ignite and inflame the desire and will in all of us to bring out the best in each other. By working together we overcome obstacles that we are unable to change by working alone. By giving our gifts, energy, and our hearts to each other we become empowered to build a future we desire. This is the gift of the circle of support."
>
> *George Ducharme, One Candle Power*

Upon completing this chapter, you should be able to:

- Identify your support system.
- Identify strategies to find out about neighborhood groups.
- Demonstrate the benefits people in a social network get from one another and give to one another.
- List ten considerations when building a relationship.
- Identify facilitator do's and don't's.

Section 1

Social Networks

To help an individual increase his or her social network, watch how long it takes for someone to become important to the individual. Observe how much contact takes place between the individual and others before they seem to become important to him or her. Does the individual "warm up" to people quickly? Are there some types of people he or she is more drawn toward? Is the person actively involved in a social setting or on the sidelines watching others?

Noticing these and other signs can help you understand the individual's interests in a social setting as well as his or her need for support.

Looking at My Support System

What do I already have?

Name	How am I supported?	Is it what I want?	Is it enough?

What do I want? ***More support – or a different kind of support?***

- **At Work**

Type of support?	*From whom?*

- **At Home**

Type of support?	*From whom?*

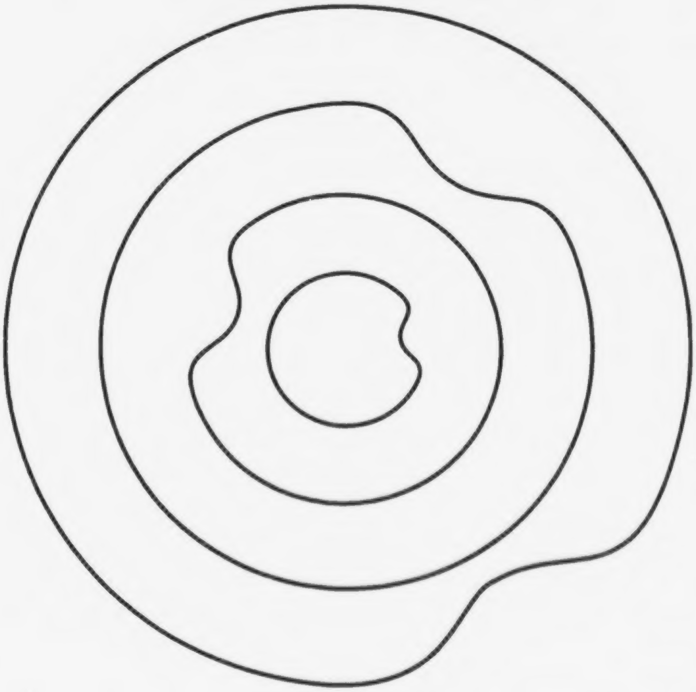
- **From Friends**

Type of support?	*From whom?*

There are various types of possible support: trading support, giving feedback, nurturing, playing, getting together, inspiring, teaching, empathizing, sharing job or career resources, advising, listening without judgement, being there, etc.

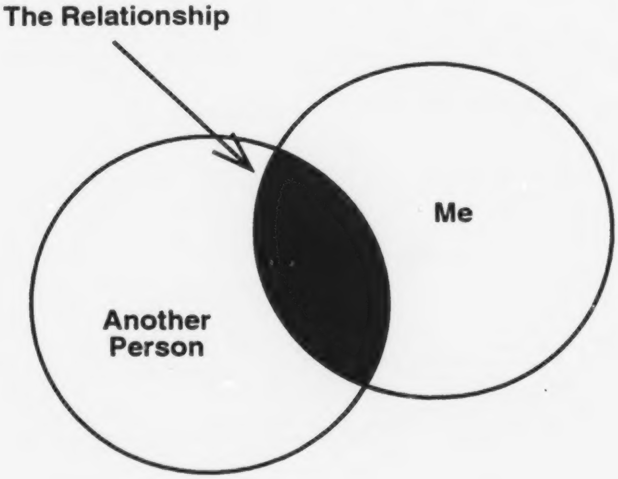
Draw in the rings below. You go in the center ring. Who are the people in your life who are important to you? They go in the ring next to you. In the next ring go people in the next closest group to you. Continue until you reach the outermost ring.

Notice the "notches": these are the places people fit. It's that person in each ring that could be closer to you with some effort. What steps can you take for him or her to be closer?

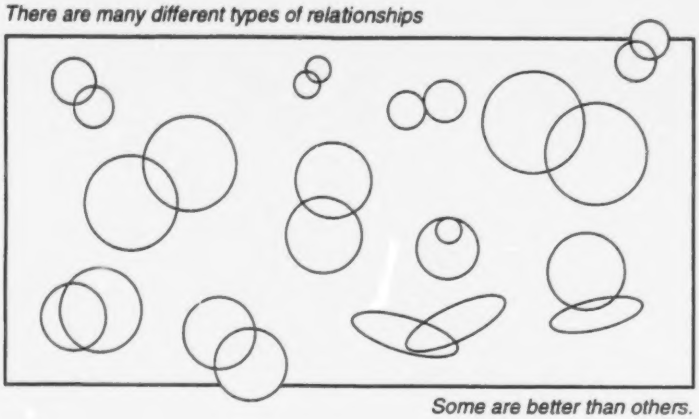


I Get Support from My Relationships with Others

I can identify the persons in my personal support network and the areas in which they will be involved.


The Relationship
Me
Another Person

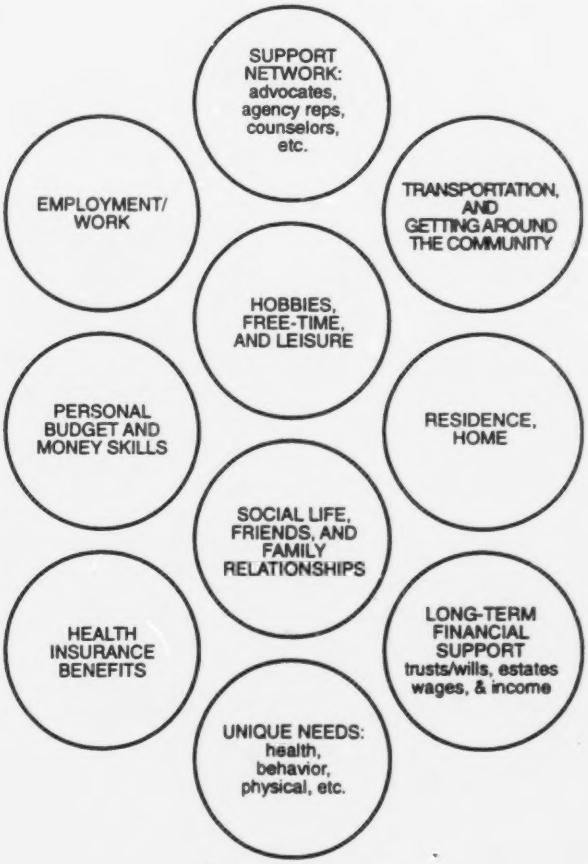
There are many different types of relationships



Some are better than others.

My Personal Support Network

I can identify the persons in my personal support network and the areas in which they will be involved.


SUPPORT NETWORK: advocates, agency reps, counselors, etc.
EMPLOYMENT/ WORK
TRANSPORTATION, AND GETTING AROUND THE COMMUNITY
HOBBIES, FREE-TIME, AND LEISURE
PERSONAL BUDGET AND MONEY SKILLS
RESIDENCE, HOME
SOCIAL LIFE, FRIENDS, AND FAMILY RELATIONSHIPS
HEALTH INSURANCE BENEFITS
LONG-TERM FINANCIAL SUPPORT trusts/wills, estates wages, & income
UNIQUE NEEDS: health, behavior, physical, etc.

BEST COPY AVAILABLE

Finding My Friends

Use this exercise to plan and discuss opportunities for making friends and developing relationships. After filling this out together, have the individual fill in his or her circle of friends, including those he or she would like to become closer to.

What do you do to make friends?

What I Do — Who I'd like to know better

In my neighborhood

At work

In school

In my place of worship

In activities

Finding Out About Neighborhood Groups

If you're looking for ways to include individuals you work with in neighborhood activities or looking for activities for individuals to become involved in, here are some ideas:

- Read meeting schedules found in the local newspaper.
- Collect directories of community organizations from the public library or ask the United Way organization for a listing, or seek out self-help directories.
- Talk to people at local institutions such as parks, recreation centers, churches and community centers and ask what groups schedule regular meetings in their buildings.
- Conduct a phone survey of local residents and ask, "In what do people participate in this area?" You may first want to send a letter to residents in a selected area about your interest in area activities and explain that a phone call will follow the letter to ask for their suggestions of area activities.
- Ask the librarian about local meetings and the times they meet. Many meetings are held in the local library.
- Ask for group names and meeting times. Many meetings are held at local parks.
- Call local bowling alleys and ask about leagues, etc.
- Call churches and ask what local meetings are held in their building, the types of groups, and the times they meet.

Adapted with permission from *Getting Connected: How to Find Out About Groups and Organizations in Your Neighborhood* (1988) by Kathy Nakagawa, Center for Urban Affairs and Policy Research, Northwestern University and Department of Rehabilitation Services, State of Illinois, 2040 Sheridan Road, Evanston, Illinois 60208; Telephone, 312/491-3395.

What Friends Do For Each Other

Here are some benefits that people in a social network get from one another and give to one another in social relationships:

- **Information:** People in a social network give and get information from one another. For example: "Do you know any good plumbers?" "Where did you get those shoes?"
- **Feedback:** People in social networks give and get advice from each other. For example, it might be technical – having to do with work – or personal, or relating to social skills or manners.
- **Assistance in making major life decisions:** People in social networks help each other make big decisions about events such as career changes, moving, marriage, or school plans.
- **Emotional support:** People in social networks help each other when happy and sad situations affect their lives. Some of those situations might be death in the family, unhappy relationships,

problems with children, or celebrating happy events like births and weddings.

- **Material aid and service:** People in a social network help each other out in small and big ways. For example, someone may care for a neighbor's pet while out of town, a friend may loan money until pay day, and a neighbor may loan tools or a ladder for a project.
- **Access to others:** People who are part of a social network are introduced to other friends and may extend their base of friends at all levels. A friend may invite another to a party or social gathering where new people and potential friends are met. The neighbors may have a block party where one meets new people.
- **Companionship:** People who are part of a social network have others they can plan activities with and have as companions.

Adapted with permission from *Social Support Manual* (1989) by J. Stephen Newton, Neighborhood Living Project, Specialized Training Program, 135 College of Education, University of Oregon, Eugene, Oregon 97403-5215.

Levels of Support to Help Improve Social Life

The following are some ideas to offer support to individuals to help improve their social lives. These ideas may be useful to you in helping individuals establish and maintain relationships.

- Write social life objectives in the IHP/IEP/IFSP.
- Use staff meetings to notice and assign tasks to each other that may naturally result in improved social experiences for the individual throughout the course of his or her day.
- Set weekly goals for socially integrated activities. Break down those ideas into small steps so the individual is always working on a manageable piece of a social life skill area.
- Rotate the responsibility among staff members to be the social director for a week. That person planning social activities for the week can be non-staff people (volunteers), kitchen staff, office staff, as well as paraprofessionals and teachers, counselors, etc.
- Encourage individuals and their families (or group home leaders) to volunteer to have an in-home social activity. For example, someone may host a Monday night football party get together, another may host a walk around the area lake or neighborhood.
- Help individuals join local clubs, organizations and churches that share his or her common interests. Then help the individual focus on getting involved. Help in the organizational process (such as registration fees, paper work, finding the location and time, arranging transportation) until he or she is

settled into the activity.

- Explain and encourage the idea of reciprocity. For example, as part of friendship, first I do something for you (i.e. buy you lunch) then you do something for me (i.e. you take me out to lunch). Explain that to keep friendships alive and growing, people have to take turns calling each other and making plans together.
- Accompany the individual on the first meeting or first activity into the community to help facilitate ease and comfort for him or her and the community people. Help them understand each other. If you work with children and have made suggestions about activities to the parents, offer to attend the first activity with the parents and the child.
- Find out the individual's interests. Introduce him or her to people with similar interests. Friendships are usually based on similar interests. Sometimes people don't know what their interests are. They need to try different activities to find out what appeals to them. ("How do you know you won't like it if you haven't tried?")
- As a paraprofessional, you also need to build your own social network and social integration system through community activities. Activities are more likely to be spontaneous if you (or someone else on staff) have had prior involvement in the activity your are encouraging. Regular activities that are done over and over are reinforcers for friendships (fast food restaurants, bowling, concerts, movies, etc.).
- Teach the individual to independently go out and do activities (as much as possible) that will facilitate his or her own social life. For example taking the bus, biking, setting up own arrangements and plans, shopping alone, going to recreational areas alone, all create a sense of independence and enable the possibility of friendships developing in a natural way.
- Decrease or replace behaviors that compromise social life. Help the individual improve his or her ability to have a better social life by teaching him or her acceptable social behaviors.

Adapted with permission from *Social Support Manual* (1989) by J. Stephen Newton, Neighborhood Living Project, Specialized Training Program, 135 College of Education, University of Oregon, Eugene, Oregon 97403-5215

Role-play Situation

Pretend you're running a weekly staffing and discussing the social situation Toby is in. Use the "Levels of Support to Help Improve Social Life" ideas on the previous pages to help come up with some ideas. Do this in small groups, then share your solutions with the entire class.

Situation

> The school psychologist, the nurse, the regular classroom teacher, the paraprofessional, and the physical education teacher get together for a team meeting every Tuesday at Harley High School to discuss Toby's progress in all areas. On this particular Tuesday, the physical education teacher states that he has been watching the interaction with Toby in gym class, the locker room and in the hallways. Because Toby weighs 220 pounds and is a star on the football team, the guys always want Toby on their team in class, but they seldom interact with Toby any other time. Toby has appeared especially dejected lately and the physical education teacher talked to him about it last Friday. Toby says he wants to make friends with the guys, but they're always too busy for him, or ask him to do impossible things with them, like drive them to a party (Toby works night and doesn't drive). The coach would like to facilitate some friendships for Toby. Role-play the situation to find your group's solutions to this dilemma.

Feel free to adapt the situation, if needed, to be more suitable for your group.

Ten Considerations When Building Relationships

All relationships follow the pattern below to some degree or another. When working to facilitate friendships for, and with, persons with disabilities, some of these considerations may be hard to comprehend. You may need to do some direct teaching of these ten considerations and it's important for you to know and understand this.

- Relationships are always possible. There's potential for relationships to form but never certainty that they will.
- People have a range of relationships from acquaintances to lovers which makes their lives complete and integrated.
- There's no real logic to how relationships develop and progress. Painful struggles can be a sign of great growth. Conflict is normal and okay. Absences do not necessarily mean the relationship is over.
- Rejection is part of the relationship making process. It's typical to meet people and decide you do not choose to make friends with them.
- Relationships build slowly and strengthen over time. They're full of ups, downs and struggles.
- Relationships start from small beginnings and can't be determined from only one meeting. Trust takes time to build and friendship is built on trust.
- Experiences, opportunities, and relationships are all connected. The more opportunities a person has, the more

chance they have for relationships.

- Building relationships takes a lot of self-confidence and time. Be patient.
- Relationships are always in a state of growth.
- Relationships do not depend on a person's abilities and attributes, but on comfort and ease between two people

Adapted with permission from *Leisure, Integration, and Community* (1992) by P. Hutchinson and J. McGill, Concord, Ontario: Leisurability Publications, Inc.

Facilitator *Do's* and *Don't's*

These are important guidelines for you as a paraprofessional to know when helping to facilitate friendships.

Don't's

- Choose friends for individuals.
- Decide who is appropriate and who is not appropriate to be a friend.
- Structure activities to meet their needs over the interests of the individuals.
- Decide for individuals what their interests will be.
- Assign a "friend" to someone and then feel they have helped develop friendships and their job is done.

Do's:

- Have a positive relationship with the individual (this models appropriate friendly behavior).
- Have skills in including individuals in groups so they can develop a sense of what it's like to be a part of a friendly group.
- Support the process of finding and making friends by emphasizing the individual's strengths.
- Act as an unobtrusive supporter and facilitator.
- Help plan appropriate interest related activities.
- Encourage the individual to advocate for personal needs in a relationship.
- Offer and encourage one-on-one experiences with peers to develop confidence in relationship building skills.

Adapted with permission from *Connecting Students: A Guide to Thoughtful Friendship Facilitation for Educators and Families* (1992) by C. Schaffner & B. Buswell, PEAK Parent Center, Inc., Colorado Springs, CO 80918.

Summary

This chapter defined a social network, discussed ideas for developing social networks, and offered you an opportunity to identify your support system. As a paraprofessional, you're in a position to support people you work with as they develop their social network. Social networks empower one another to build futures that they desire.

Questions to Ponder

- What new information did you gain from doing the activity "Looking at My Personal Support System"? How could you incorporate this activity for individuals with whom you work?
- People in social networks give and receive a variety of things: information, feedback, assistance in making life decisions, emotional support, material aid and services, access to others, and companionship. Can you identify people that give you these types of support? Can you identify people that *you* give these types of support?

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Chapter Nine

Facilitating Friendships

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Introduction

Knowing how to support individuals with disabilities with whom you work to start friendships can strengthen the network of support and the entire empowerment process. This chapter discusses key strategies you can apply and build on in individual situations.

Upon completing this chapter, you should be able to:

- Identify strategies that could assist people with disabilities to start friendships.
- Identify activities to facilitate friendships.

Section 1

How to Facilitate Friendships

In many cases, you – as a paraprofessional – may be put in a situation where you can best facilitate friendships between two individuals. You may see the spark of a possibility for a friendship in a work setting, school setting, a neighborhood or community setting, or a residential setting. If you take the initiative to start a friendship for two people, they may be able to continue the relationship with your support. The following suggestions and activities may help you in your efforts to help individuals with disabilities start friendships.

- Survey the situation. Look at the various social and work situation the individual will be in. Who does the individual seem to gravitate towards (or visa-versa)? Is he or she lonely? Does he or she talk about anyone particular in the neighborhood? How does the individual communicate with others? Is there someone he or she makes more of an effort to be with? Does he or she seem to be angry or upset if unable to get or keep the attention of someone. *These might be messages about possible friendships that could be developed with some facilitating on your part.*
- Review the individual's day. Think of times throughout the day that these possible friendships may be nurtured. Are there times that you could facilitate a natural type setting for two friends to get to know each other better? *Timing is everything. What key times can you plug in friendship facilitation?*
- Estimate how much facilitation will be needed. How independent is the individual? How willing is he or she to self-advocate and reach out to establish his or her own relationships? When does the individual really need your help to facilitate relation-

ships? (It may be only at certain times in certain circumstances.) Figure out how much help is needed. *Don't be too intrusive. Offer only the level of support that is needed.*

- Determine what you can do that will be most helpful to specifically facilitate the friendships and make a plan. Think about whether you should help in finding opportunities, in interpretation, or in accommodation. At what level is the individual's relationship development? *Start where the individual needs the most help.*
- Think about who would be the best facilitator in the situation. Each situation will be different. Who's the most logical person to assist in each situation? When you get together in your team meetings, discuss who, based on relationship with the individual, personality, and job assignment, is best in handling each facilitation. *Use the most logical staff person to facilitate based on individual situations.*
- Explore and assess ways to use natural everyday situations to create and develop relationships. Often the best opportunities for friendship development are right under your nose. What is going on in the individual's everyday life? How can you capitalize on that to facilitate friendships naturally. *Sometimes the best opportunities are also the simplest.*
- Follow-up on situations. Relationships have their ups and downs. Once you've helped get a relationship started, you need to be available to monitor the progress and support the individual in those ups and downs. This will help the individual to become confident and understanding about relationship development so he or she can become independent in developing friends in the future. *Continue to be there for the individual during the development of the friendship.*
- Disappear as soon as you can. As soon as the friendship has taken on a life of its own, back away and let it develop without your facilitation. At the same time, let the individual know you care and are there for support. *Once the relationship is established, back out.*

Adapted from *Connecting Students: A Guide to Thoughtful Friendship Facilitation for Educators and Families* (1992) by C. Schaffner & B. Buswell, PEAK Parent Center, Inc., Colorado Springs, CO 80918.

Activities to Facilitate Friendships

Here are some ideas you can use to help facilitate friendships. Think of each person you work with individually: which of these would work in your experience and understanding of the unique needs of each person?

- Give individuals opportunities to show off their strengths to the others in the group.

- Tell others about special interests or talents of individuals in the group.
- Show positive ways to deal with unpleasant situations that an individual may create to show the group coping skills for the individual's behavior.
- Be available to demonstrate strategies, answer questions, interpret situations, and answer concerns as needed.
- Help individuals learn how to communicate well with others by serving as a role model for good communication and interaction with others.
- Encourage individuals to communicate honestly, whether they are telling about fears, concerns, questions, or issues.
- Encourage discussions about friendships in the natural setting of work or play. Talk about what friendship involves so that others can talk openly about their friendship experiences.
- Brainstorm together for solutions to issues and problems between friends.
- Offer individuals times to honestly talk about their strengths and weaknesses.
- What other activities would you encourage to facilitate friendships in your setting?

Adapted from *Connecting Students: A Guide to Thoughtful Friendship Facilitation for Educators and Families* (1992) by C. Schaffner & B. Buswell, PEAK Parent Center, Inc., Colorado Springs, CO 80918.

Summary

This chapter offered suggestions and activities that you as a paraprofessional could use to help individuals with disabilities start friendships. These included surveying the situation; reviewing the person's day; identifying how much facilitation is needed; exploring ways to use natural situations; following up; and disappearing as soon as possible.

Questions to Ponder

- Have you ever helped someone with a disability start a friendship? What strategies were successful and how could you tell? What about strategies that didn't work? How could you tell?

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Chapter Ten

Planning for the Future

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Introduction

As you work with individuals with disabilities, encourage them to self-advocate, and facilitate the development of friendships, you're empowering these individuals to make their own choices about the lives they want to lead. You help them to have the rights to which all people are entitled. It's important to end this module on promoting self-determination and facilitating friendships and socialization skills with a discussion about current trends in planning that will lead to individuals who are more empowered and in control of their own lives and making their own choices about who they choose as friends and to associate with.

Upon completing this chapter, you should be able to:

- Describe MAPS and Personal Futures Planning.
- Identify do's and don't's of person-centered planning.

Section 1

Promoting Friendships and Self-Advocacy Through Futures Planning

There are two planning strategies that also help ensure, in a more structured way, positive empowerment and planning for the individual's future. One strategy is called MAPS (Making Action Plans) and the other is called PFP (Personal Futures Planning). Both utilize the people in the individual's life who know and care about him or her to identify and move toward desired goals. These two strategies on planning for individuals with disabilities are unique because they include not only professionals, but also the individual, family, friends, and peers without disabilities. MAPS is generally associated with students, and PFP with adults, but each can be used in a wide variety of situations. Each is an ongoing process that builds on the individual's capacities.

MAPS

MAPS uses a two-step process:

- Key questions are asked to create a picture of the person and to establish a direction for the group. Those questions direct the group about the needs, interests, abilities, and desires of the individual.

- Certain people are targeted who will develop specific action plans. These people are selected based on their knowledge of the individual and their expertise in the area where the plan will be developed. For example, if the individual's MAPS states he or she needs to develop social skills in the community, a recreation specialist may develop that part of the plan.

After the plan is made, alternatives and adaptations are made as needed. Because Personal Futures Planning is becoming very popular as a method of planning with individuals with disabilities today, we will focus primarily on this strategy.

Personal Futures Planning: Steps

Personal Futures Planning creates a personal profile of the individual's life. There are eight steps to the personal planning: the details and sequence of each step vary for individuals, but each process includes the following components:

Step 1: ***Identify Capacities***

- Map out relationships: Who's important to the focus person?
- Map places: What are the patterns of community life for the person?
- List personal preferences: What gifts (special talents or abilities) does the person possess?
- Clarify personal dreams and desires: What goals does each individual have for him- or herself?

Step 2: ***Identify a Planning Group***

The individual asks the people he or she would like to ask to work together in his or her planning meeting. These people agree to meet on a regular basis to learn together and plan for things to happen for the focus person. They use a relationship map for this planning.

Step 3: ***Clarify a Personal Future***

The person and his or her group work together to clarify goals so they share a common vision of what they are trying to accomplish by working together.

Step 4: ***Identify Obstacles and Opportunities***

Obstacles, fears, and barriers to desirable futures are identified. These barriers offer a focus for problem-solving and for networking with other groups who face similar barriers.

Step 5: ***Generate Strategies***

The groups meet regularly (about once every six weeks) to review what they have learned, accomplished, or encountered as new barriers or opportunities. Groups brainstorm to generate new strategies and directions for future activity.

Step 6: ***Make Commitments***

Following each review and brainstorming session, individual members make commitments to work on specific strategies. Members choose the strategies they have the energy to work on.

Step 7: ***Take Action***

Group members take action. Many groups focus initially on learning more about community resources, program models, and other barriers they face.

Step 8: ***Reflect on What the Group is Learning Together***

Every meeting is a time of reflection, but periodically (about every six months) the group will meet to look again at "the big picture," to re-focus, and to summarize their accomplishments.

Adapted from *One Candle Power: Building Bridges into Community Life for People with Disabilities* by P. Beeman, G. Ducharme, & B. Mount, Communitas, Inc., P.O. Box 374, Manchester, CT 06040; telephone 203/645-6976

In Planning Futures, Remember...

In order to help sharpen the vision and recognize capacity in everyone, remember the following when planning futures:

Do	Don't
• Look and listen long enough to find the capacity	• Concentrate on labels
• Seek abilities not commonly valued in our society today (i.e. the ability to be present or to bring people together)	• Be put off by visible evidence of labels
• Focus on the abilities of all people in the support system	• Prejudge a person because of a label
• Focus on the unique opportunities of each association in a neighborhood & community	
• Build on strengths that an individual has, not the weaknesses	• Don't dwell on disabilities

Adapted from *One Candle Power: Building Bridges into Community Life for People with Disabilities* by P. Beeman, G. Ducharme, & B. Mount, Communitas, Inc., Manchester, CT 06040.

Futures Planning: Scenarios

To become more familiar with the process of futures planning, read the following three scenarios and then, in class, discuss the benefits of futures planning for each person.

Scenario I: Gordon

Gordon is a handsome seventeen-year-old man with a good sense of humor who really enjoys sports. He has been classified in the moderate–severe range of mental retardation, has had some serious medical problems beginning at an early age, and has some serious behavior problems such as hitting others.

The persons involved in his planning group included his mother, special education teacher, and social worker. His father was either unable or unwilling to attend meetings. Gordon has no siblings and no interactions with neighbors or friends in his area.

Gordon's mother had been complaining about various things regarding Gordon for a long time. As a result of the futures planning process, she started really becoming an advocate instead of just a complainer. She also started to get real support from other members of her family, instead of just sympathy.

The long-range dreams for Gordon and his family included finding a trustworthy doctor, finding a respite program where the parents could be away from home on vacation for two to three weeks at a time, and finding a friend for Gordon for his after-school hours.

Gordon's mother started to take on more responsibility and learned to ask for help when it was needed. Because of the need for respite care, she began a letter-writing campaign to the county commissioners. She wrote, but also got her relatives and people in the group to write letters about the lack of respite funds. Inspired by these efforts, the social worker also started looking into county resources. As a result of both these actions, the county opened up respite funds again. Gordon has been receiving respite care at least one weekend a month now for over a year.

It used to be rare for Gordon's mother to take him out to events. But since the futures planning, his mother has taken him out more into the community. One evening a month, they attend adaptive community recreation sessions in which people play guitars and/or banjos for interested audience members, whether disabled or not. Information on other community friendship and recreation programs has also been sent to Gordon's mother, and work is continuing on the ongoing challenge of finding friendships outside school.

During times that have been stressful with certain doctors and other medical personnel, the school physical therapist has gone with Gordon and his mother to medical and orthopedic appointments to support the mother. Gordon's communication skills have also been re-evaluated to help him experience more success in letting his needs and wants be known.

As Gordon is experiencing more success in his school activities, his mother has become much more positive. She has learned much more about asking for and getting support, and about active advocacy for her son.

Scenario II: Cindy's Wheels

I've had the privilege of working with Cindy and participating in the development of her personal futures plan. Cindy is an adult who has cerebral palsy, and a degree of borderline retardation which sometimes means she also carries that label – but sometimes she doesn't.

Cindy is a strong advocate for herself, and – long before it was popular – she pushed the system (and herself) to move into her own apartment. Ten years ago, she put herself through Courage Center's apartment training program and since then has been living in her own apartment with a personal care attendant. Some time ago, Cindy achieved for herself many of the things that the system is just now seeking for people with disabilities: an independent living situation, full integration in the community, and time to spend with friends and loved ones who care.

At her initial futures planning meeting, Cindy told us that she had tried to get a new motorized wheelchair the year before but her request had been rejected. Her old chair was ten years old, broke down a lot, and was showing definite signs of wear. It seemed reasonable for her to have a new chair. I speculated that Medical Assistance probably rejected her request due to an omission or an error in the application process.

Her planning group discussed other options than a new chair. A friend of Cindy's who also uses a motorized chair talked about the possibility of buying a new motor if Cindy's request was rejected again. We realized that what was really needed was for someone to be willing to dig through the red tape for her. I felt that was where I could be useful. Even though I knew nothing about the process, I knew enough to start asking questions.

I soon learned that what Cindy really needed was a medical expert to assess her chair, her positioning, and her needs. After all of the assessments, the expert would formally submit the request for the new wheelchair. In order to begin the process, it was necessary for her own physician to make the necessary referrals. This entire process was lengthy and took nearly a year to complete.

Members of the planning group supported her in a variety of ways during this time. We talked with her physician and the positioning clinic. We made appointments for Cindy, arranged for her to be there for her appointments, and sometimes even accompanied her. During this time, I talked to companies that manufacture motorized wheelchairs and had their sales representatives attend some of the appointments with Cindy.

It was exciting for Cindy to pick out the features of her new chair: the color and style of the frame, the color and fabric of the upholstery, and the type of foot rests. It wasn't difficult to see the group's enthusiasm as we ventured into this project. It was so contagious that the sales representative for the wheelchair manufacturer got caught up in our enthusiasm and called us the very moment he heard that the application for the new wheelchair was approved. "I am putting the order in today! Just thought you would like to know." We had a mini-celebration upon learning this news – "mini" because Cindy still had to wait for eight weeks before her new chair would be delivered.

When the chair finally arrived we had a party to celebrate its arrival and to congratulate ourselves for hanging in there. It's a wonderful chair which Cindy says gives "a smooth, quiet and dependable ride!"

Scenario III: Helen's Life

Family is and always has been the central focus of Helen's life. She has an excellent relationship with her mother, who lives in Minneapolis. Her brother lives with their mother, and often takes Helen under his wing, taking her various places. Her sister has also always been a strong ally.

At the time we began dreaming of an "ideal vision" for Helen's future, she was living at a state regional center. She was involved in a supported employment job in the community and loved her work. Helen participated fully in the futures planning process and let those of us in her planning group know what she wanted to accomplish in her life.

Her own vision for the future includes living in her own apartment close to her family. She wants a dog to care for and easy access to transportation. Being close to shopping malls and recreational activities is important. She wants to cook her own meals and have enough money to buy the things she needs. Church is very important to Helen and she hopes to be able to help a pastor with church activities. Her dreams for her future are fairly ordinary and she doesn't expect too much.

When the staff started working on moving Helen out of the treatment center, they were unable to move her directly into her own apartment. Since her plan was developed, Helen's left the regional treatment center and moved to a group home in southwestern Minnesota. Fifteen people with disabilities live in the home and there are two people in each bedroom. Helen has a job at a motel in town which she likes very much.

The futures planning process gave Helen the chance to say what *she* wanted. The process gave direction to the placement process, in terms of what's important to Helen. It put her dreams to paper and some of what she wanted has happened. Without the process, what Helen wanted wouldn't have been articulated.

Helen's sister also lives in her new home and the two women enjoy each other's company. They have re-established their relationship and are now the best of friends. They frequently picnic and enjoy a variety of activities together. A local taxi provides them access to excursions into the community and shopping at the local mall. Helen visits her mother occasionally, using the bus to get to and from Minneapolis. There are many churches near her home where Helen can get involved. She doesn't yet have a dog, but hopefully this, too, will become a reality.

Helen seems very happy with her move from the regional center to the group home. This is only the beginning of the movement toward Helen's dream. The planning group has given input to the group home staff on her visions. Helen's mother wants to keep the planning charts up in her house. With the continued support of Helen's planning group, there is good reason to believe all her visions will be realized.

These three scenarios are adapted from *Listen, Lady, This is My Life: A Book About Futures Planning in Minnesota,* by A. Amado, developed by the Minnesota Governor's Planning Council on Developmental Disabilities

Summary

Two types of person-centered planning were discussed in this chapter: MAPS and Personal Futures Planning. The person-centered planning encourages individuals with disabilities to be empowered to take more control of their lives and to have their dreams identified and supported. As a paraprofessional working with people with disabilities, you could encourage and support this type of person-centered planning.

Questions to Ponder

- Have you ever participated in a person-centered planning meeting? How did this process differ from other planning meetings you've attended?
- What are ways you could encourage using a person-centered planning process with individuals with disabilities with whom you work?
- What benefits do you see in using person-centered planning? For whom?

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Appendix A
The Dignity of Risk

By a parent whose son is in a supported work program in Richmond, Virginia

What if you never got to make a mistake?

What if your money wasn't always kept in an envelope where you could get it.

What if you were never given a chance where you could do well at something?

What if you were always treated like a child?

What if your only chance to be with people different that you was with your own family?

What if the job you did was not useful?

What if you never got to make a decision?

What if the only risky thing you could do was to act out?

What if you couldn't go outside because the last time you went outside it rained?

What if you took the wrong bus once and now you can't take another one?

What if you got into trouble and were sent away and you couldn't come back because they always remember you're "trouble"?

What if you worked and got paid forty-six cents an hour?

What if you had to wear was your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of the grocery shopping but weren't allowed to do *any* because you weren't able to do *all* the shopping?

What if you spent three hours every day just waiting?

What if you grew old and never knew adulthood?

What if you never got a chance?

From *Changing Expectations/Planning for the Future: a Parent Advocacy Manual* by Dorothy Sauber, ARC Minnesota, Minneapolis, Minnesota.

Appendix B
Family Empowerment

By Rud Turnbull

Once upon a time, a decade ago,
Two families found a way to go
Through life with pain. or else with gain,
Despite being almost the same.

"There's not much we can do, except be tossed
Hither and thither, and hope what we've lost
Can be recouped, just a little bit.
That's sufficient, more than a whit."

So said the one, whom we'll call *Doubt.*
They piqued the interest of the family *About.*
Doubt was skeptical, a powerless clan.
About was determined, a strong woman and man.

"Disability motivates. It's our spur.
It causes change in us and in her.
Our daughter's world is different in kind.
But some skills we have, and others we' ll find."

Said *Doubt,* power out of their range,
"You'd better accept things you cannot change."
Answered *About,* putting on armament,
"We disagree. We're feeling empowerment."

Over the years, *Doubt* never learned what to do,
While *About* changed themselves and systems, too.
Doubt took a road traveled by some few.
About chose a path that has helped even you.

With doctors and teachers *About* raised their voice,
"Work with us! Please honor our choice!"
And as they lived in their little town,
Strengthening ties began to abound.

Neighbors and friends, and clergymen too,
All quickly learned what they could do.
They surrounded *About* with their generosity,
Providing a different social security.

In my very simple and none too elegant ditty lie most of the elements of the debate on empowerment. How useful is a poem about empowerment? It has two uses. First, like many good poems, it distills the essence of a complex concept. After reading it, the reader *needs* to know nothing more. Second, it lends itself to analysis that further explains a complex concept. After reading the poem, the reader who *wants* to know more about the concept may dissect the poem and, by discovering nuances in it, achieve a deeper understanding. Here, I begin with the elementary and move to a more sophisticated understanding of empowerment.

Two Different Approaches

Let's begin by considering the poem ‘s two families. The *Doubt* and *About* families each have a child with a disability. There is where their similarities end, however. *Doubt* is not motivated by the fact of disability. *About* is. *Doubt* accepts things pretty much as they are, content to be reactive. *About* acts on that motivation by identifying their resources and vowing to find others; they become proactive.

Choosing the path of least resistance, D*oubt* makes very little difference in their own family's life, much less in any other family's life. *About* opts for the more difficult path and thereby makes a powerful impact for themselves and others, too.

Elements of Empowerment

The essential elements of empowerment are present in A*bout* but not in *Doubt*: *motivation,* plus *action* that uses inherent *skills,* develops other *resources,* and *impacts* one or more situations.

Empowerment is also a *process*. *About* experiences empowerment immediately upon the birth of their daughter with a disability. They achieved more of it, over the years, much as anyone acquires skills through a developmental process. "Once upon a time, a decade ago," *About* took action, and continued to take it "over the years."

Empowerment exists when the family *feels* they can have some control over their lives. *About* said, "We're seeking empowerment," indicating they feel they can have some control over their lives.

Empowerment also consists of the fact that the family does achieve some mastery over some aspect of their lives. *About* took a path that helped themselves and "even you."

The Responsive Context

But a family is just one of the actors in the empowerment drama. In every family ‘s life, there are many others. Even the family that feels the most empowered and takes the firmest action will find that it makes no difference unless others respond positively. Empowerment requires a *responsive context*. Thus, *About* said to providers, "Work with us! Please honor our choice!" Obviously, the providers listened to them "*About* changed themselves and systems, too." By changing systems, *About* "chose path that has helped even you." In short, they created a responsive context for themselves and for others as well.

Thus, empowerment is a purposeful developmental process aimed at helping a family gain mastery over its life and environments, consisting of motivation, skills, and resources, and causing changes in the family and in the systems with which it relates.

Origins of Empowerment

We still have more to learn. But we have to leave the poem's text. Like most analysts, we need to examine the context within which the poet wrote. Let's start by examining empowerment's origins.

Empowerment originates in political theory about democratic government. Government of, by, and for the people is the familiar phrase – one that asserts that the people have power over their governments.

Empowerment also derives from social programs of the early 1960s. These programs lived by the phrase "Power to the People" and embodied it in model cities and community action programs. Nowadays, politics of the right and the left both pay tribute to empowerment but advocate different strategies.

Empowerment finally reflects psychologists' efforts to help people be healthier and to cause their communities and public policy to respond more to their needs.

Thus, empowerment derives from political theory, social programs, and policy reform proposals and from several disciplines. Accordingly, it is best understood when each of these perspectives is taken into account.

Criticisms of Empowerment

Good poetry deals artfully with important subjects. Certainly no one (especially not I) would applaud this poem's artfulness. Let's move beyond form and style, however, and consider this potential criticism: yes, the poem addresses a significant issue but it does so in wrong-headed ways. Can that be said of this poem? Perhaps so, on two grounds, but both are without merit.

Families Already Have Power

Some people object to the very term and concept of empowerment. They say that families already have "power" and that no policy or professional (in the disability field) can "give" them what they already have. We believe this view does not represent an accurate understanding of empowerment.

The fact of the matter is that by far the greatest number of families do have and feel that they have inherent power, motivation, skill, and potential for impact on systems that serve them and their children with disabilities. The poem acknowledges this fact by featuring the A*bout* family. At the same time, some the case with the *Doubt* family. Empowerment does not necessarily mean that someone has to give power to a family. That could be the case. It equally can be the case that a family, such as *Doubt,* takes the initiative to become more empowered.

It is also true that most families have to share power with professionals. Sharing can be useful, or not, for the families. In sharing their lives and power, *About* changed themselves "and systems, too." The poem's message is clear: public policy should indeed foster shared decision making between family and professional, and it should encourage family participation in policy and research activities.

Empowerment Research is Misguided

Some also say that research on empowerment is misguided. Research on shared decision making and family/professional collaboration. they argue, legitimizes power in professionals, whereas power should lie only or at least primarily in families. They also contend that empowerment research assumes families are dysfunctional and can best be understood only from a "deficit" perspective.

Again, we disagree. Research on the process, components, and impact of family empowerment does not assume that the families are dysfunctional or deficit based. Rather it assumes that families are indeed inherently strong (like Ab*out*). Their empowerment behavior (motivation, skills, resources) is worthy of study. Only with study will we know how to increase empowering behavior in others and how empowering behavior makes the families' worlds more responsive. These worlds include the formal service systems and the informal or other mediating structures, such as religious, community, or other groups. Thus research about families in context is desirable; and research about systems change is, too.

Indeed, too much research already has examined families' "deficits/pathology/brokenness." True, we need to understand what causes them stress and how to help them cope. But even more, we need to know why A*bout* approaches life with a sense of purpose and strength ("But some skills we have, and others we'll find... We're feeling empowerment.") This is so because A*bout*'s empowerment affects not just professionals but also "neighbors and friends, and clergymen too." *About* affected their informal or mediating structures. And they did so in a most remarkable way: they evoked the generosity of others and thereby created a different kind of social security, a kind that no federal program can mandate.

Now, here at last is what we know and believe about empowerment, as exemplified by the poem:

- Empowerment' s origins are in political theory, social programs, and policy reform proposals, and its theoretical and research bases are in several disciplines.
- Empowerment is a process whereby families recognize their own power and use it to gain mastery over their environments.

- Accordingly, empowerment is best understood from a systems perspective, reflecting the fact that the family interacts with various environments.
- Empowerment exists when a family is able to combine its motivation with its own inherent or internal skills and with external resources and, by bringing the combination of motivation, skills, and resources to bear on their environment, cause that environment to change.

Thus, empowerment warrants research of individuals, families, professionals, and other individuals in certain contexts. In the disability field, the usual context is the formal service provider system. Because families do not relate to only that context, empowerment research should also focus on families' interactions with informal or mediating structures.

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Appendix C

Empowerment: Dependence vs. Independence

By Frank G. Bowe, Ph.D.
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Empowering Americans with disabilities to take charge of their own lives never has been more important – or more possible. Yet in many ways, it's never been more difficult.

The events of the past few years have led many to believe that the job already is done, at least in major part. They're wrong.

The fact is that, with respect to the bulk of the population of Americans with disabilities, we're standing still. The Americans with Disabilities Act (ADA) will help. How much it helps will depend not only on how it is implemented and enforced but also on how energetically Americans with disabilities adopt the lifestyles it makes possible. For millions, this means radically altering how they live their lives.

That's ironic in light of the efforts we've made to empower people with disabilities in this country. In this paper, I will raise the question: "What steps can we take now to empower the population?" I'll begin by outlining what we say we're doing, then track what we're actually doing. The evidence seems to suggest that we've empowered people with disabilities in legislation only; they've not yet incorporated into their thinking the life altering choices new laws have given them. Until they do, they won't consider themselves to be empowered.

Dependence versus Independence

The empowerment movement, broadly speaking, is that thrust in which we as a nation say to individuals with disabilities: "You can live a life of achievement, independence, and self sufficiency. To assist you in that effort, we as a society will do our part. We'll enforce federal laws protecting you from unfair discrimination in education, employment, and everyday life. We'll also invest billions of dollars to provide you with the skills you need to support yourself in gainful employment. And we'll remove community barriers that stand in your way."

It's a beautiful sentiment, particularly to a civil rights activist like myself. I've spent twenty years helping to fashion this "independence message." I believe in it and I think most Americans with disabilities agree with me. The evidence, though, is that we still have much more to do for this message to take hold.

The counter movement, which I sometimes call the "dependence" alternative (Bowe, 1980), dates from the 1954 amendments to the Social Security Act creating Social Security Disability Insurance (SSDI) and the 1974 amendments creating Supplemental Security Income (SSI). These programs, together with Medicare (for SSDI recipients) and Medicaid (for SSI recipients), sent a very different message to Americans with disabilities. They say: "Society has an obligation to support you as people who should not be obligated to support yourselves. we'll provide a safety net as long as you need one." Although this message has been modified by 1980 and 1986 amendments to the Social Security Act so as to remove some "work disincentives," the core message remains the same today. That's particularly true because many SSI recipients don't believe the Social Security Administration when it says that those changes make it safe for SSI recipients to work to support themselves.

The evidence is that the "dependence" message has taken hold, and remains dominant, despite all efforts to wean dependent individuals with disabilities from it. The 1986 Louis Harris and Associates poll (ICD/Harris, 1986) found that two thirds of adults with disabilities who were on entitlement rolls would rather be working. That's what they said. So one would expect that at least some would move from aid rolls to pay rolls.

It doesn't seem to be happening. The first data from the 1990 Census of Population and housing show us that as few adults with disabilities were working to support themselves in the 1990 as was the case in 1980 (Bowe, 1986a). The 1990 census found that 60.6 percent of "working-age" (16–64 year-old) adults with work disabilities were not even participating in the work force. These 7,782,459 adults neither worked nor were actively seeking employment when the census was taken in April, 1990 (Bureau of the Census, 1992).

That only 39.3 percent of adults with work disabilities were in the labor force in 1990 – after the 18-million strong growth in jobs in the 1980s – is bad enough. That so few worked despite some $20 billion in federal, state, and local spending each year on special education, more than $2 billion in federal and state outlays on rehabilitation annually, and untold sums in private and public investments to remove architectural, transportation, housing, and communication barriers is, if anything, worse.

The recent numbers we have tell us that a majority of working-age adults with disabilities neither work nor actively seek employment. Today, putting it baldly, most adults with disabilities do not work. That's hardly the result we would expect from the concerted efforts we made to empower the population.

There's another concern. The costs of maintaining large numbers of Americans with disabilities on the entitlement rolls has mushroomed in recent years. Today, the SSA counts more than eight million persons with disabilities on its SSI and SSDI rolls. Entitlement programs such as SSI, SSDI, Medicaid, Medicare, and veterans benefits total more than $290 billion on the federal level alone. Whether we as a nation can continue to pay such costs is an open question.

Whether we should, given that these programs disempower millions of Americans with disabilities, is equally questionable. I have great difficulty believing that as many as eight million people with disabilities truly cannot work, given modern adaptive aids and accessible personal computers.

These programs are controversial among people with disabilities. Some argue that SSI and Medicaid are, in effect, welfare "handouts" that people can get just by being disabled, without having to work for them. Individuals with disabilities who worked hard to get an education, and then worked even harder to get and keep a good job, sometimes resent the fact that others with the same kinds of disabilities do not have to work to buy food and clothing, pay the rent, and receive medical care. Seen in this light, SSI and Medicare can rob people with disabilities of the incentives needed to become independent, self-supporting citizens.

Other advocates are angry because SSI and Medicare have many outdated rules that make it difficult to get off these aid rolls and onto payrolls. Some youth and adults with disabilities who benefit from SSI are still concerned they may lose eligibility if they engage in "substantial gainful activity," which usually means earning more than $500 a month. To place that figure in context, consider that it means making the minimum wage at a 35-hour-a-week job. A 1986 amendment – section 1619 – to the Social Security Act allows some individuals to earn much more and yet keep Medicaid coverage. This program was designed to encourage SSI recipients to accept jobs paying more than the previously allowed amount. In fact, relatively few SSI recipients have left the Social Security rolls for payrolls under the section 1619 program.

These SSI and Medicaid rules disempower millions of Americans with disabilities. For some, SSI and Medic aid are necessary; these people, most of whom are severely disabled, have no real choice. Others can be helped, however. The foundation for empowering these people is largely in place.

Empowerment Legislation

We mark the beginnings of the modern disability empowerment movement with the Rehabilitation Act of 1973. PL 93-112 required development of an "Individualized Written Rehabilitation Plan" (IWRP) by each client and his or her counselor. Two years later, in the Education for All Handicapped Children Act of 1975, Congress mandated the preparation for each child with a disability of an "Individualized Educational Program" (IEP). This document was to be prepared by school officials with the approval of the child's parents (and, where appropriate, of the child as well).

In addition, parents were granted remarkable rights to access all school records about their child, to appeal decisions with which they disagreed, and to materials in their native language. Later versions of the law, now called the Individuals with Disabilities Education Act (IDEA), added an Individualized Family Services Plan (IFSP) for infants, toddlers, and their families, and an Individualized Transition Plan (ITP) for adolescents age sixteen or over. Taken together, these written plans provide meaningful opportunities for people with disabilities and their families to take charge of their lives. Ideally, IEPs, ITPs, and IWRPs are developed in concert, permitting individuals with disabilities to map out a coordinated strategy for reaching personal goals.

Other legislation has reached deep into the private sector to empower individuals with disabilities seeking access to community life. The Fair Housing Amendments Act of 1988 permits persons with disabilities to make access modifications in apartments and condominiums, forbidding landlords to bar such alterations. In addition, real estate agents, brokers, and landlords are required to practice nondiscrimination in all aspects of their work with prospective tenants and homeowners. The law further requires that all new apartment, cooperative, or condominium buildings with four or more units be constructed to be both accessible (wide doors, ramps, etc.) and adaptable (controls, cabinets, etc., that are readily lowered or raised).

The landmark Americans with Disabilities Act of 1990 granted to individuals with disabilities the most far reaching civil rights accorded persons with disabilities by any nation in the world. Reaching deep into the private sector, the ADA requires virtually every employer with fifteen or more workers to practice nondiscrimination in employment and to make reasonable accommodations as needed so that individuals with disabilities may perform jobs for which they are qualified. It ended twenty years of acerbic national debate about access to transportation by mandating access to mass transit, commuter rail, and intercity buses.

The Act requires millions of businesses serving the public, such as stores, doctor's offices, entertainment centers, sporting complexes, and laundry establishments to make their services available on an "equal enjoyment" basis to customers with disabilities. The ADA also extended to persons using Text Telephones (also called TDDs) full and equal access to the nation's public switched telephone network, including all telephones connected to any of the country's 1,600 local exchange companies (LECs) and all of its long-distance carriers.

In addition, the Act granted to individuals with disabilities the right to charge violations of their civil rights in private-sector employment, in state and local governments, in "places of public accommodation" such as shopping malls and movie theaters, and in telecommunications.

These laws provide a framework for empowering people with disabilities. For Capitol Hill, the greatest challenge now is to create a single, coherent national policy on disability. To date, the two streams of legislation have proceeded almost unaffected one by the other. The 1974 SSI law and its 1980 and 1986 amendments, on the one hand, established and perpetuated the "dependency message." A separate stream of laws beginning with the 1973 Rehabilitation Act and the 1975 education law, and continuing through the 1990 ADA, created and expanded the "independence message." The task for the U.S. Congress now is to articulate to the American population of people with disabilities a single message. That will take time. Meanwhile, there is much we can do.

Vehicles of Empowerment

The Americans with Disabilities Act charged federal agencies, notably the Department of Justice, the Equal Employment Opportunity Commission, and the Department of Education, with providing technical assistance and information about the ADA. Notable among the efforts undertaken to carry out these mandates are a $1 million contract from EEOC to the Disability Rights and Education Defense Fund (DREDF) to train disabled activists on helping to implement the ADA. The Department of Education has funded a network of ten ADA technical assistance centers, as well as several materials development centers. The Department of Justice awarded grants for more than a dozen projects aimed at accelerating compliance by such covered entities as restaurants, hotels, and labor unions.

Still, in view of the census information, we need something more if we are to fully empower tens of millions of Americans with disabilities. I like the idea of looking to "independent living centers" (ILCs). The Rehabilitation Act, as amended in 1978, created what is now a 466-strong network of local centers for independent living. Most congressional districts have at least one such center. The centers are governed and staffed largely by individuals with disabilities. These advocates are active at the local level, especially in peer counseling. Their focus on the community and their tradition of peer support position them ideally as vehicles of empowerment. I would like to see them focus their energies on informing community residents of their rights.

An excellent local project for an ILC would be to encourage each area resident with a disability to speak up at each store, restaurant, hotel, and other covered entity he or she visits in the normal course of events. It may not take much more than a comment – "I'd like to shop here, and I could, if you'd do what the ADA calls for." Multiplied over millions of people saying this in tens of millions of businesses, such small steps would do more to stimulate implementation of the Act than almost anything I can think of.

The women's movement accelerated in the late 1960s and early 1970s because of exactly such actions. Millions of women became aware of entrenched paternalistic attitudes and made the small, individual decisions to assert themselves as equals. The women's movement asked each woman to act on her own, at home and at work. That was something virtually every woman in America could do. Centers for independent living can ask Americans with disabilities in the 1990s to take similar small, local steps. Importantly, such actions permit these individuals with disabilities to begin to take responsibility for their own lives. As they learn what the laws require, and ask that local companies do those things, they'll empower themselves.

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Appendix D

Advocacy: Noun, Verb, Adjective, or Profanity?

by Linda Cress Bonney and Sandy Moore

Depending on your perspective and your personal experiences, advocacy can be exciting, challenging, frustrating, frightening, or a relief. Advocacy is often misunderstood. Yet, all of us at one time or another have found ourselves acting as an advocate for our children, our students, our friends, or ourselves.

For the purposes of this article, *advocacy* is defined as information, advice, and representation provided to individuals and their families to assist them in acquiring appropriate services for a person with a disability. An *advocate* is a person trained to provide support, advice, and legal representation to persons with disabilities.

Law, regulation, and policy set out a process and procedural safeguards within each service system for persons with disabilities. This is true of social services, education, and the health care systems. The process of accessing any service includes at minimum, application, eligibility, assessment, service plan, service delivery, and delineation of financial responsibilities. When this process is working well, there is no need for an advocate. When there is conflict or disagreement in accessing or providing services, then an advocate might be called. The primary purpose of an advocate's involvement is to resolve conflict. The advocate's role is to serve as a "guardian of the process" to ensure that the required steps are taken to identify and meet the needs of the people that each system is mandated to serve.

Families are often referred to an advocate by other families or professionals who recognize that the process has been derailed and that an outside party will be needed to get it back on track. Persons often request the assistance of an advocate as a last resort. Many have been threatened with discontinuance or reduction of services. Some of these people will have attended many meetings, without results, while others were unaware of their right to convene a meeting at all. Some will have identified and repeated the problem as they've been passed from one agency to the next, while others may not have found someone willing to listen or help.

At this point, families and professionals are often feeling angry and frustrated. Family members may be reluctant to involve an advocate, not wanting to be seen as troublemakers and being fearful of possible retribution to their family member with a disability. Professionals may be feeling defensive. People with disabilities, their families, and friends need to realize that they may be in that painful position of choosing between "not rocking the boat" and getting what is needed for the person with a disability.

It is not the role of an advocate to dictate the outcome, but rather to direct the process to reach the desired outcome, which is implementation of services designed to meet the unique needs of the person and family. The first step for the advocate is to gather the information necessary to identify the problem and determine where and how the process got derailed. The advocate will often be seen as a persistent person who asks and re-asks many questions regarding the details of what has taken place, the players involved, and the roles and power of these players. The advocate will need to look carefully at all of the relevant assessments and information to ensure that there is documentation supporting the professional recommendations and decisions that are being made. This is where the advocate's knowledge of the laws and regulations is critical in order to determine the appropriate strategies to employ.

The advocate's job is not to ensure that all participants are comfortable or happy, but to ensure that the person with a disability gets the needed services. Yet, a successful advocate will be an experienced problem solver, and will work to move the team towards resolution in a focused, positive manner. A skillful advocate will always be aware that their presence is temporary, while the person with a disability and family will continue working with many of these service providers on a long-term basis.

While working through specific issues, the advocate has a responsibility to help build others' confidence and skills so that all the people involved will be better equipped to deal with problems in the future. In addition, the advocate attempts to build the supports necessary for the individual and family to continue to informally advocate for them selves, and for them to know and follow the processes that ensure provision of services throughout life.

There are several things that persons with disabilities and family members can do to more effectively use advocacy. First, they can learn as much as possible about the program(s) they are working with, and, before problems arise, ask for written information on their rights and the appeal process for each program. They can also identify which professionals are responsible for assisting with which types of problems. Secondly, as problems arise, it's important that individuals and families identify what they want and/or don't want in services before contacting an advocate. And finally, it's better to request assistance before doom appears inevitable. We have yet to meet an advocate with wings, and there is seldom a magic answer that offers a "quick fix" to long-standing problems.

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Reprinted with permission from *Impact: Feature Issue on Family Empowerment,* Summer 1992, 5(2), published by the Institute on Community Integration (UAP), University of Minnesota Minneapolis.

Appendix E

Confessions of a Paraprofessional

By Mary F. Hayden

I am a social worker by trade. I entered the profession with the belief that social change could occur through the various methods of community organization, such as social protest, advocacy, lobbying, whistle blowing, and self-help action groups. Through the years I have participated in sit-ins, advocated for individuals and classes of people, and led self-help groups. Because of these experiences, I view myself as a "good guy".

When asked to plan and coordinate an all-day working conference on the issue of self-advocacy, I was excited to be given the opportunity to educate other professionals and to show them how to mend their ways. However, I found this holy campaign to be my own personal awakening. I was surrounded by many teachers. Through their actions and accounts of their personal experiences, they taught me that professional good intentions may hinder people with disabilities from speaking out for themselves. I found that even a "good guy" has room for improvement.

Prior to meeting the other participants at the conference, the word "client" would flash before me during conversations with them. I would become angry and tell myself that the correct term was "consumer". After I met with everyone at the conference, I was gently told that the "correct term" was *people with disabilities*. Through working closely with everyone, the labels quickly went by the wayside.

Lesson 1: ***Don't label people.***
Get to know the person as an individual.

As a member of the helping professions, I found myself wanting to help. I wanted to do things for people. For example, some people had not stayed in a hotel and, as a result, they did not know how to check in and out, charge meals to the room, and tip bellhops. Initially, I took care of a number of these activities. I eventually learned to explain the hotel "system" to people and let people take care of themselves.

Lesson 2: ***People have the right to make choices in everyday life.***
Practice what you preach.

I wanted to protect people. This behavior ranged from telling someone that the area around the hotel wasn't safe to wanting to keep tabs on people. A series of events occurred that made me realize that my need to protect was a reflection of my focus on people's disabilities rather than their capabilities.

One afternoon several people decided to go to the Martin Luther King Center. I decided to use a rented car. One individual with a physical disability stayed behind. To my surprise, the person who "stayed behind" was at the Center waiting for us. I later found out that he preferred to travel independently rather than with a segregated group. Several other participants periodically left the group to either be by themselves or to meet new people.

Lesson 3: ***People have the right to discover, explore, and experience life.***

During the conference, the group worker within me became nervous; the group controlled the group process. Some people didn't talk while others monopolized the time. A few people were overbearing, some were more articulate than others, and some were more socially skilled. Initially, I believed someone (a professional) had to work the group dynamics to insure that the most relevant information was brought to light. Because of this, I listened to people who were brief, accommodating, articulate, socially skilled, and focused. However, the facilitator was able to get beyond the veneer. He listened and heard each person's message. Everyone made a contribution to the conference and it was duly noted.

Lesson 4: ***Don't judge a book by its cover.***
Listen to the person.

As these and other events occurred, I had a series of conversations with the other participants about when a behavior is a reflection of caring and support or when it's a reflection of control and overprotectiveness. People shared their experiences through these conversations. They all provided examples of a professional's expertise and personal agenda overriding the wishes of a person with a disability. They gave accounts about how the social service system hinders personal growth. They shared moments where others judged their lifestyle. These conversations helped me to remember that I chose to work in the field to assist and support people with disabilities. They allowed me to re-affirm my belief that people should experience life to the fullest.

Lesson 5: ***The manner in which a person chooses to experience life may be inconsistent with our philosophy. These differences need to be simply acknowledged and appreciated. No value judgement is necessary.***

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Reprinted with permission from *Impact: Feature Issue on Self Advocacy*, Winter 1990/91, 3(4), published by the Institute on Community Integration (UAP), University of Minnesota, Minneapolis.

Appendix F

Out of My Old Life and Into My New One

By Michael J. Kennedy

I grew up in three New York institutions. In 1982, when I was twenty-one, I moved into a group living situation in the community called a supportive apartment. I lived with three other men with cerebral palsy, and we were supervised by staff whenever we were home. The supported apartment was much better than the institution, but in the six years I lived there I learned everything I could learn and was ready to be on my own. Also, the program was funded by Medicaid and had too many rules and regulations, like having to have goals and a service plan.

I knew what I wanted, but I needed help to get it. So I started talking to the director of the program about being on my own. I was listened to in one way, but not in another way because nothing was happening. What I had to do to get my point across was to threaten to move back into the institution near my family in the Adirondack Mountains area. The director got wind that I was actually going to do it, and the agency staff didn't want that. I know it would have been a mistake, and I didn't want to quit my job at the Center on Human Policy, but I felt my back was against the wall. That was the beginning of my getting my own home.

The agency told me about a new program they had just received funding for. It was called a Family Care program, but what it does is to match a person with roommates and the other supports he or she needs. One of the staff at the supported apartment, John, called me into the office one day and asked me if I would consider setting up a home with him and his roommate Gordy. I agreed, with the understanding that I didn't have to follow Medicaid rules or have a service plan. I wanted to make my own decisions. I made it very clear that when it was time to leave the program, I could just go, no strings or questions asked.

As time went on, the coordinator of the Family Care program met with John and me. I told her what I wanted in terms of supports and a home. Part of her job was to help us find a place. The exciting part is that we had a friend who used to work for the agency who was into buying real estate. One day I was kidding with her and said, "Why don't you buy a house that would be easily accessible and I would rent it from you?" About a week later she told me she had bought a house! At first I thought she was kidding, but then when she took me and John over to see it I knew she was serious. We called the coordinator on the phone.

John and I then started meeting with her on a regular basis. It was actually pretty easy to set up the supports I would need, like physical therapy and my orthopedic doctor, because I could just take what I had from the apartment and transfer them to my new house. The supports I didn't have at the apartment were just added on. For example, I had to arrange attendant care with one of the agencies in town. Medicaid would pay for all of this when I was on my own because I kept my Medicaid eligibility.

Always keep in mind that it may not be as easy for someone else as it was for me to set it up. The important thing you have to remember is that you should be involved in every aspect from start to finish. You, the individual, must have the supports built around you, and not be made to fit into a program that wasn't designed just for you. This is true regardless of how severe your disabilities are. It's very important that you have the say about how your wants and needs are dealt with.

If you work at an agency, I'd hope that you would go along with the individual on how he or she wants to live. You don't have to agree, but they have the right to live like anyone else.

I've lived on my own for the last two years. Through this period John and I have talked about moving down south. We both like the South for a number of reasons. One is that we both have family down there, and they have been asking us to move down there for quite a while. The most important reason is that both John and I felt we needed a change in our lives, we needed something new, and we needed to move on. So, we are moving to a town near Atlanta, Georgia. I am very excited about this move.

Michael Kennedy was formerly the Self-Advocacy Coordinator at the Center on Human Policy at Syracuse University, and is currently a consultant to the Center.

Reprinted from *Impact, 3* (4) Winter 1990/91, Research and Training Center on Community Living and the Institute on Community Integration at the University of Minnesota.

Appendix G
ADA Requirements Fact Sheet

Employment

- Employers may not discriminate against an individual with a disability in hiring or promotion if the person is otherwise qualified for the job.
- Employers can ask about one's ability to perform a job but cannot inquire if someone has a disability or subject a person to tests that tent to screen out people with disabilities.
- Employers will need to provide "reasonable accommodation" to individuals with disabilities. This includes steps such as job restructuring and modification of equipment.
- Employers do not need to provide accommodations that impose an "undue hardship" on business operations.

Who needs to comply:

- All employers with twenty-five or more employees must comply, effective July 26, 1992
- All employers with fifteen to twenty-four employees must comply, effective July 26, 1994.

Transportation

- New public transit buses ordered after August 26, 1990, must be accessible to individuals with disabilities.
- Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed route bus services, unless an undue burden would result.
- Existing rail systems must have one accessible car per train by July 26, 1995.
- New rail cars ordered after August 26, 1990, must be accessible.
- New bus and train stations must be accessible.
- Key stations in rapid, light, and commuter rail systems must be made accessible by July 26, 1993, with extensions up to twenty years for commuter rail and thirty years for rapid and light rail.
- All existing Amtrak stations must be accessible by July 26, 2010.

Public Accommodations

- Private entities such as restaurants, hotels, and retail stores may not discriminate against individuals with disabilities, effective January 26, 1992.
- Auxiliary aids and services must be provided to individuals

with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.

- Physical barriers in existing facilities must be removed, if removal is readily achievable. If not, alternate methods of providing services must be offered, if they are readily achievable.
- All new construction and alterations of facilities must be accessible.

State and Local Government

- State and local governments may not discriminate against qualified individuals with disabilities.
- All government facilities, services, and communications must be accessible consistent with the requirements of section 504 of the Rehabilitation Act of 1973.

Telecommunications

- Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices.

This document is available in the following accessible formats: braille, large print, audio tape, electronic file on computer disk, and electronic bulletin board. Call 202/514-6193.

For more information about the ADA, contact the U.S. Department of Justice, Civil Rights Division, P.O. Box 66118, Washington, DC 20035-6118, 202/514-0301 (voice), 202/514-0381 and 202/514-0383 (TDD).

Appendix H
The Kindness of Others

By Roberta L. Juarez

"I have always depended on the kindness of others..." is one of the most memorable lines from one of my favorite plays and until very recently it pretty well described the way people with disabilities interacted with society, or didn't interact. Well, *no more!*

Thanks to the newly-passed Americans with Disabilities Act (ADA), Americans with disabilities are now on a more even ground with their able-bodied brothers and sisters. Jobs, transportation, telecommunication, and public accommodations should soon be more fairly accessible.

As an adult with cerebral palsy who spent far too much effort and money on a college education to be told she wouldn't be considered for a professional position because her "co-workers would feel uncomfortable around her", I am thrilled to know it will soon be illegal to consider my disabilities rather than my abilities. Even if I need something changed to make my job easier to perform, Uncle Sam says it's okay as long as it's reasonable.

When this dream job affords me that well-deserved three-week vacation, I should be able to take a few things for granted: I'll be able to travel to my destination using the transportation system of my choice; I'll be able to ask for an accessible hotel room and actually expect to get one; and if I want to call a friend who has a speech or hearing impairment just to remind her that she's at work and I'm not – an appropriate telecommunication system will be available.

If I were still in high school, the ADA would still prove important. Even though it does not touch directly on education, the ADA will strongly impact "education" outside of the classroom. No longer will an adolescent be denied a trip to the movies with his friends because the theater is inaccessible, or the bus doesn't have a lift. No longer will he be unable to call a classmate to commiserate over the unfairness of today's pop quiz because his friend doesn't have as TDD. He can use a free, confidential telephone interpreter service. Although these activities may seem unimportant, even trivial, they are not. Some of the most important lessons are learned outside of the classroom.

More obvious is the fact that his education will really be worth something because when he's ready, if he's qualified, he will get the job.

One other thing about the ADA – it eliminates the excuses for parents and individuals with disabilities not to be assertive when it comes to accessing the services they need for their children or themselves. The days of relying on the kindness or paternalism of others are gone. People with disabilities have just become first-class citizens. It's up to all of us to make the most of it.

Roberta L. Juarez, M.S., R.D., works for the Metropolitan Center for Independent Living in Minneapolis.

Appendix I
Section 504 Fact Sheet

What is it?

Section 504 is a section of the Rehabilitation Act of 1973 which protects the rights of persons with disabilities. It prohibits agencies or organization which receive federal funds from discriminating against otherwise qualified individuals solely on the basis of disability.

What is a disability under 504?

An individual is determined to have a disability if he or she:

1 Has a physical or mental impairment which substantially limits one or more major life activities (walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, performing manual tasks);
2 Has a record of such impairment; *or*
3 Is regarded as having such an impairment.

This can mean that a school-age child who has an attention deficit disorder and does not qualify for special education services may still be entitled to accommodation in regular education under Section 504.

What are "reasonable accommodations" under 504?

Accommodations must achieve meaningful equal opportunity, must consider the functional limitations of the person and alternative methods of performance. Some examples could be the following: modified testing, preferential seating, taped textbooks, readers, tailoring homework assignments, etc.

Are evaluations and IEP required?

A district must evaluate "any person who, because of handicap, needs or is believed to need special education or related services". Evaluation is also required prior to a significant change in placement.

A written plan describing placement and services must be developed. A formal IEP is not required, but decisions will be made by a group of persons. Placement decisions must be based on information from varied sources and must be documented. All information must be considered. Decisions must be made by a group of persons who are knowledgeable about the child, the meaning of the data, and placement options.

What are the responsibilities of schools?

Schools must provide assurance of non-discrimination, designate an employee to ensure compliance, provide grievance procedures, identify and locate all qualified children with disabilities who are receiving public education, provide notice of district's 504 responsibilities and procedural safeguards. The procedural safeguards are as follows:

1 The right to written notice
2 The right to review records
3 Theright to an impartial hearing

What if there appears to be a violation?

The Office of Civil Rights investigates Section 504 complaints. Minnesota is in Region Five, 300 Wacker Drive, Chicago, Illinois 60606; Telephone 312/353-2520.

Appendix J
Who Can Teach Change Better?

By Beatrice Roth

In the early days when I was first asked to be a chapter advisor with Speaking for Ourselves, finding guidance material on my role was almost impossible. I was told, "Your members and your heart will teach you." How true, and the lessons began immediately.

As a guest observing my third monthly meeting of the group, the President once again welcomed me and expressed appreciation at my interest. Before fully understanding what was happening, I found that I had been nominated and voted in as a chapter advisor. I know now that this was the start of a whole new way of thinking, a way of reacting – or better still, *not* reacting.

To assist others, to step in and help, had been instilled in me since childhood. But, to "assist" often meant to take over and do it myself. I learned that an advisor does not take over. An advisor supports and is a friend. The leadership role belongs to members.

For example, my natural tendency is to push my own opinion of who's best suited for chapter officers, which are elected on a yearly basis. But, time has taught that an advisor listens first to what members have to say. Their fingers are on the pulse of what is best for them. Those with top leadership abilities have already taken the foreground over the previous year and members have an instinctive knowledge of who can best represent the group.

When an individual speaks out on his or her own behalf, the message is from deep within. Who better knows what needs to be changed? Who can better describe the pain experienced and the frustration of unanswered needs? Who more has felt the effects of people ignoring their simple entreaties for everyday wants and desires? Individuals need only to be encouraged to step forward and speak out. Expressing reassuring faith in our members as individuals, exploring options, affirming abilities, is a vitally important role of an advisor. It can't be faked. It starts with listening as a true friend, prompting someone who has been devalued by society to expose their wounds, to trust you, to believe in him- or herself. It's not easy for people that have been repressed and relegated to the background to freely speak out about what's hidden inside. But it's important for others to hear and understand the effect of their often unintended actions that hurt. The story needs to be told. Again, the advisor's part is that of a student learning from a teacher, our members, who can best instruct from self knowledge. Their insight gleaned through life's heartaches is the best teaching tool in bringing about change. An encompassing circle of experience, learning, educating, and support is shared by members and advisors alike.

One way the story is told is as members speak out on issues dear to them during the annual Speaking for Ourselves Conference. This event, planned, executed and presented from start to finish by Speaking for Ourselves members, is directed toward educating the world at large, parents, professionals, and staff about issues such as real jobs, community integration, and awareness of the many capabilities individuals with developmental disabilities offer to today's society. An event of this size is only successfully accomplished through the dedication, systematic planning, and teamwork of members from all chapters. Throughout this, the advisor is a strengthening backer, an affirming friend, providing transportation, paperwork and support backup. But, most important is the vital role of encouragement, being there when needed to prompt someone to take that scary next step.

My friends at Speaking for Ourselves inspire me to greater heights in life. It's why being an advisor is one of the greatest enjoyments of my life, just rubbing elbows with so many wonderfully courageous and determined people. It's a two-way street where each learns and teaches, where all of us together in Speaking for Ourselves educate those in the world around us in the ways to a better life not just for individuals with disabilities, but for us all.

Beatrice Roth is Advisor for the Montgomery County Chapter of Speaking for Ourselves in Montgomery County, Pennsylvania, 215/549-0550.

Appendix K

NICHCY Newsletter on Self-Determination

NICHCY

TRANSITION SUMMARY

National Information Center for Children and Youth with Handicaps

NUMBER 5 1988

SELF-DETERMINATION

The purpose of this issue of *Transition Summary* is to acquaint readers with the issues of independence and self-sufficiency -- sometimes called self-determination or self-advocacy -- that young adults with disabilities face as they look toward the future. In this issue, we also offer parents guidelines, insight, and practical advice on helping their children with disabilities cultivate some of the skills they will need to function more independently as adults.

People with disabilities have diverse needs and abilities. Someone with a physical disability may have different needs from someone with mental retardation; likewise, someone with learning disabilities may have needs that differ greatly from someone with an emotional disturbance. In spite of this diversity, however, most people with disabilities have this in common: they can express their own viewpoints, and can make informed decisions about matters that affect every aspect of their lives.

This *Transition Summary* does not attempt to present the diverse needs of people in different disability groups or the needs specific to any particular disability group. Instead, the focus is on the need for young people with disabilities to take charge of their own lives and to speak for themselves in an effort to overcome discrimination, segregation, and unequal opportunities based on disability. Also discussed are the rights and needs of these individuals to live with dignity and respect; to have the same opportunities to fail and to succeed as people without disabilities; and to no longer be seen as individuals perpetually dependent on welfare and charity.

In most families, an adolescent's transition to adulthood is a stressful period. For families with children who have disabilities, the transition may be even more disruptive. The forms that the stresses may take and the ability to react to those stresses will vary from family to family, depending on the number of family members, the family's geographical location, their social and financial resources, and their personal values and beliefs (Brotherson et al., 1986).

For parents, the period of transition means learning how to gradually let go, becoming less protective, and fostering in their child a sense of self-assurance, self-reliance, and responsibility. For many young adults, transition means leaving school and/or home, and undergoing personal change as well as changes in their relationship with their [illegible]. It means having more independence and more responsibility.

Recently, people with disabilities have begun to consider themselves a minority group denied basic rights, such as attending public schools, becoming employed, marrying, and bearing children (Funk, 1987). Indeed, only in the past two decades have many rights and freedoms -- taken for granted by nondisabled persons -- been made available to people with disabilities. According to a recently conducted nationwide survey of 1,000 disabled people, "there are clear signs of an emerging group consciousness among disabled persons" (*The ICD Survey of Disabled Americans*, 1986).

Today, the focus of civil rights legislation for individuals with disabilities is "to assist individual disabled people to achieve a normal life experience as a citizen, not to create a nearly normal person as has been the focus of human service providers" (Funk, 1987). Along with the need to be recognized as people with their own rights, there is a call to reconsider the ways in which society thinks about and treats disability and the disabled. According to Thomas (1982), "One of the failures of our society is...its [inability] to comprehend the normality of handicap. It is the overwhelming insistence that we perceive and encourage 'the disabled' to perceive themselves as deviant that is the root of the problem." Thomas further observes that cultural attitudes toward those with disabilities have progressed through three stages: in the first, the person with a disability was considered helpless; in the second phase, skilled professionals became involved in "helping" those with disabilities; and in the third stage, persons with disabilities exhibit determination and question their roles as passive recipients of help (Thomas, 1982).

According to Gartner and Joe (1987), what is needed in education and other human service fields is "a recognition of the range of humankind, the awareness that all individuals possess both strengths and limitations, in varying mixtures and to different degrees." This requires that we avoid the use of terms and language that either deny the fact of the disability or that dispel reality. "Being disabled is not a 'challenge'... [the disabled] ... voluntarily undertake. Nor is it that we are merely 'differently abled.' We are disabled; there are just some things we can't do, at least not as quickly or as easily as other people" (Browne et al., cited in Gartner and Joe, 1987).

This issue of Transition Summary *contains articles about self-determination and becoming a good self-advocate. Ironically, much that has been written about these subjects has come from professionals rather than from people with disabilities. Each of the articles in this publication, however, reflect the experience of someone who has grown up with a disability.*

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THE MANY FACETS OF SELF-DETERMINATION

by Michael J. Ward

In the article that follows, the author describes his concept of self-determination and discusses parents' roles in encouraging their children with disabilities to trust and respect themselves, to gain self-assurance, and to become as independent as possible.

Michael Ward is the Chief of the Secondary Education and Transition Services Branch at the Office of Special Education Programs, the U. S. Department of Education. Before holding this position, he was a rehabilitation counselor for adults with developmental disabilities in Brooklyn, New York.

He grew up in Brooklyn, where he attended public schools. Recently, he completed a Ph. D. in Special Education at the University of Maryland.

Dr. Ward has cerebral palsy and uses a wheelchair.

What is Self-Determination?

Self-determination has been defined in a variety of ways. The *American Heritage Dictionary* (1976), defines it as "the determination of one's own fate or course of action without compulsion: free will." Another source defines it as "decision according to one's own mind and will" (*Webster's New World Dictionary*, 1972). A common element in both definitions is the importance of people taking control, without undue external influence, over what affects their lives.

Self-determination refers both to the attitudes which lead people to define goals for themselves and to their ability to take the initiative to achieve those goals. Acquiring the personal characteristics which lead to self-determination is a developmental process that begins in early childhood and continues throughout adult life. While it is important for all people to acquire these traits, it is a critical -- and often more difficult -- goal for people with disabilities. They must first shatter the pervasive stereotypes which imply that they cannot, or perhaps should not, practice self-determination.

The traits underlying self-determination include self-actualization, assertiveness, creativity, pride, and self-advocacy. The terms "self-actualization" and "assertiveness," borrowed from modern psychology, are important in the development and personal growth of all individuals. Self-actualization refers to realizing your potential and living your life accordingly. Assertiveness is being able to express your needs clearly and directly and to act and speak out with self-confidence (Des Jardins, 1986). Creativity is the ability to be innovative; to move beyond stereotyped images and expectations. Pride in yourself and your abilities is a trait that translates into feeling good about the contributions you can make to society. Self-advocacy, an essential component of self-determination, refers to the ablility to act on your own behalf. This concept is an outgrowth of the grass-roots disability movement of the last 20 years, a movement which has given disabled people the right and power to take necessary, but often unpopular, actions to ensure that their basic civil rights and social and economic needs are addressed. For people with disabilities, self-advocacy is "running risks, challenging rules, and acquiring resources" (Varela, 1986). It also involves "knowing your basic human rights; standing up for your rights; taking responsibility for your life; and asking for help because you want it or need it" (McGill, 1978).

Achieving self-determination, to borrow a concept from Gestalt psychology, is definitely "more than the sum of its parts." It requires not only that people with disabilities develop inner resources, but that society support and respond to these people. Self-determination is a lifelong interplay between the individual and society, in which the individual accepts risk-taking as a fact of life and in which society, in turn, bases an individual's worth on ability, not disability.

Persons with disabilities who want to achieve self-determination need to learn how to trust and respect themselves. They also need to learn to identify their rights and needs and to find the most appropriate ways of communicating these to others. But most importantly, people with disabilities must acquire a sense of political purpose and an understanding of their rights, responsibilities, and the democratic process (Williams and Shoultz, 1984).

Historical Perspective of the Disability Rights Movement

For centuries, society as a whole treated people with disabilities as objects of pity and fear. They were viewed as incapable of participating in or contributing to society. Prior to the 20th century, societal attitudes reflected the view that persons with disabilities were "unhealthy, defective, and deviant," requiring "special institutions, services, care, and attention in order to survive" (Funk, 1987). The national policy that grew out of such attitudes emphasized the reliance of people with disabilities on welfare and charitable organizations.

Even today, many people assume that children with disabilities are segregated from non-disabled peers because they cannot learn or because they need special help or protection. Similarly, for many, the absence of people with disabilities in the workforce is obvious proof that such people cannot work. Little thought is given to the idea that people with disabilities, in fact, are discriminated against (Funk, 1987).

Despite efforts through public policy in the 1950's and early 1960's to integrate persons with disabilities into community programs, societal attitudes had an isolating effect on persons with disabilities, forcing them to identify with and participate in groups of their own kind. Goffman (1963) wrote in the classic work in disabilities literature, *Stigma: Notes on the Management of Spoiled Identity*, that the relationship of such people to informal and formal community organizations made up of their own kind is crucial to the self-concepts of group members. However, his book was written long before it was recognized that persons with disabilities could use these organizations to improve their social status, and thus reduce the stigmatizing effects of segregation and isolation. The social and political climate of the civil rights re-

> *. . . it is difficult for adolescents to be independent psychologically and emotionally from their parents when they are dependent on them for meeting their basic physical needs.*

form movement of the 1960's greatly influenced the disability rights movement. The role of people with disabilities shifted from passive dependence to active involvement. Rather than being recipients of philanthropy, they were becoming active participants in a far-reaching civil rights movement that challenged the stigmas associated with other minority groups, as well, such as ethnic minorities, women, gays, and the elderly. This shift in attitude raised the consciousness of these groups to the point where "the minority group is no longer one for whom pleas, reforms and changes are made by others, but where they themselves [those in the movement] are instrumental in provoking change" (Thomas, 1982). People with disabilities began to understand that, among their rights, they had freedom of choice and freedom to belong to and take part in society (Funk, 1987).

Along with the civil rights movement of the 1960's, local independent living centers emerged across the country. Weiner (1986) defines an independent living center as "a community-based program that has substantial disabled citizens' involvement and leadership and provides directly, or coordinates indirectly through referral, those services necessary to assist disabled individuals to increase self-determination and to minimize dependence." One of the first such centers was the Center for Independent Living, established in 1964 at the University of California at Berkeley. Its impact was far-reaching. Not only did it provide a wide range of services to the community it served, it was created by people with disabilities to meet their needs as they saw them. Thus, it became the symbol of all that those with disabilities could achieve, given the chance, and gave momentum and credibility to the independent living movement and the concept of self-determination.

The acquiring of self-determination is not limited to persons with physical disabilities. People First and United Together are two disability consumer organizations made up of people with mental retardation and their aides.[1] These organizations offer evidence that although it is often difficult for people with mental retardation to express their needs clearly, they can learn to manage an advocacy organization (with help), and can make decisions that affect their lives. Self-advocacy cannot be reserved for the "elite" among individuals with disabilities. People with mental handicaps who cannot communicate well can and should be encouraged to contribute in self-advocacy groups. With time and help, they, too, can learn the skills they need to participate in issues that affect their lives.

Adolescence: The Critical Stage for Self-Determination

Manus and Manus (1983) discuss the theory that adolescence is a phase in which young adults, both with and without disabilities, test their own knowledge, try out new roles, and rely on peer groups, rather than their families, for support. Generally, it is a phase in which young people challenge parental authority in order to assert independence and gain control over their lives as a necessary part of successfully moving into adulthood.

Many young people with disabilities have difficulty with this process of transition for several reasons. First, it is difficult for adolescents to be independent psychologically and emotionally from their parents when they are dependent on them for meeting their basic physical needs. Second, although adolescents without disabilities may encourage and reinforce the expression of differences, a disability may be a difference that they find unaceptable.

Some of the barriers that young adults with disabilities face are in fact found within the family structure. A major obstacle is not being given the right to fail. All adolescents must be allowed to "absorb the pain of failure, to react immediately to failure or to delay and react to failure later" (Manus and Manus, 1983). As children with disabilities become older, they should be given more responsibilities and the support they need to make their own decisions, even when parents feel that such decisions are not the best ones. Young people with disabilities need to learn that it is all right to fail and start over again. Failure can provide important opportunities for problem solving, decision making, and responding creatively to difficult situations. By being allowed to fail and to make mistakes, young people with disabilities can begin to develop an understanding of their abilities and limitations.

Parents and other adults can do much to encourage children with disabilities to exercise independence and self-determination. For example, children need to be included in making decisions that affect the whole family, such as where the next family outing will be, what the next family car will be, or how family time will be spent. As early as possible, children should make decisions about basic issues that directly affect them -- what clothes they wear, for example, or how their bedroom furniture is arranged.

Parents should also encourage their children to perform household chores that are within their capabilities. It has been said that parents should never do anything for their children that their children can do for themselves. This is especially sound advice for parents reluctant to assign chores or responsibilities to their child with disabilities in the belief that he or she is already overwhelmed and should avoid anything that would make life more difficult. While doing chores may take longer for some people with disabilities, most are not in any overwhelming physical discomfort. Chances are that children who grow to feel overwhelmed by their disabilities may have been treated as "special" or "sick" by parents, siblings, teachers, friends, or relatives.

An important point for parents to remember is that children challenge their parents in a sincere and necessary attempt to become independent adults. For young people with disabilities, this conflict may be more difficult or prolonged, but it is just as necessary as it is for all young adults.

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[1] The aides in these organizations are non-handicapped helpers who provide support and assistance with the development of ideas, but who do not function as leaders in the organization (Williams and Shoultz, 1982).

WHO CHOOSES?

by Bill Mitchell

Parents are a strong, stablizing force in a child's life and play an important role in helping the child develop self-confidence and a sense of independence. Parents of a child with disabilities typically want to protect the child, an instinct based primarily -- but not exclusively -- on a realistic knowledge of the child's limitations.

In the article that follows, the author discusses the need for young people with disabilities to be involved, as much as possible, in making decisions that affect their lives. He also discusses ways in which families affect their child's ability to take risks, make decisions, and live with the consequences.

Bill Mitchell works in the Governmental Affairs Office of the Association for Retarded Citizens (ARC) in Washington, D.C.. Currently, he is involved in a project funded by the Department of Housing and Urban Development to provide technical assistance in the financing and design of housing for people with disabilities.

He came to Washington on a fellowship with the National Council on the Handicapped, during which time he wrote a paper on developing leadership in the disability rights movement.

Mr. Mitchell grew up in Atlanta, Georgia, where he attended public schools. He later graduated from Georgia State University with a Bachelors degree in Philosophy. Before coming to Washington, he worked as a counselor for students with disabilities at Georgia State University and as the staff advocate for the Georgia Advocacy Office.

Mr. Mitchell has a mobility impairment.

Historically, people with disabilities, both individually and in groups, have had few opportunities to exercise choices in their lives. In his book, *From Good Will to Civil Rights: Transforming Federal Disability Policy* (1984), Richard Scotch observes that "disabled people generally have not spoken for themselves, and public policies have typically dealt with their needs in ways shaped by stereotypes of dependency."

The lack of involvement of people with disabilities in decision-making at the policy level has its roots in the lack of participation in decision-making at the individual level. Decisions affecting people with disabilities have frequently been made by others. Those disabled early in life have gone from having parents make decisions for them to having doctors, social workers, or rehabilitation counselors make decisions for them. Those raised in segregated facilities have found their chances of making their own decisions restricted even further. No wonder then, that when confronted repeatedly with the message that they must learn to take responsibility, many people with disabilities feel confused and unprepared.

What are the barriers to exercising choices? Based on my observations and experiences with other people with disabilities, I have identified three barriers that I believe restrict opportunities for young people with disabilities to learn to make their own decisions:

1. Overprotection

Ironically, those who care most about individuals with disabilities may be among the obstacles to their gaining the experiences necessary to exert more control over their lives. Typically, most parents, but particularly parents of children with disabilities, feel the need to protect their children from the pain of failure and rejection. Yet, as they mature, children will be exposed to situations that require them to make choices and abide by the consequences.

As a part of growing up, youngsters will be out in their environment -- "hanging out" with the neighborhood kids, exploring the woods beyond the back yard, or stopping at the corner store on the way home from school -- out from under the watchful eye of a parent or other authority figure. It is during these times that children begin to learn more about their own capabilities and limitations and to feel a sense of autonomy.

In some cases, the combined effect of parental concern and environmental barriers may lead to a situation in which a child with a disability is never out of the house unless in the presence of a parent or another adult. The natural tendency of parents to protect their children is reinforced by the reality of the difficulties present in the immediate environment. Parents of children with disabilities often do not have a basis of comparison for determining what are acceptable versus unacceptable risks in the environment, and consequently may lack the reassurance needed to be able to allow their children their own "space" to find their way in the world.

In my own experience as a child having a mobility impairment and using a wheelchair, I got out a lot, explored my surroundings, and played with the neighborhood kids. These unsupervised experiences were among the most important in my life. I learned about relationships and about taking responsibility for my own actions, and generally broadened my perceptions of the world around me and how I fit into it.

Compare my experiences to those of a child in a residential facility. One situation reflects the society we live in -- the real world; the other reflects a society limited by restrictions that skew the child's perception of the world. When I consider my experiences of growing up in my own community and attending a neighborhood school where I had the same restrictions as other children, and then compare them to the experiences of acquaintances who have spent a significant part of their lives in residential facilities, it is not hard to account for the uncertainty many of them feel when confronted with challenges and opportunities.

Unfortunately, for many adults with disabilities, decisions to take on new experiences are influenced more by the degree of risk involved rather than the opportunities afforded by the experiences. And while my observations are unscientific, there seems to be a direct correlation between the degree of restriction these adults had as children and their fear of taking risks as adults. If you have been told much of your life that there are so many things that are too hazardous for you to do, and if you have never been given the opportunity to test the true limits of your capabilities, it wouldn't be surprising that you would be obsessed with security.

> *The importance of receiving the message that those who care about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated.*

2. Low Expectations

Another barrier to the achievement of self-determination for many people with disabilities involves the low expectations that society has of them and consequently, that they have of themselves. As people with disabilities, we receive conflicting messages from different sources telling us: (1) that we are absolutely incredible for doing the most trivial of things; and (2) that whenever non-disabled people are around, we should let them help us do whatever we are doing because, surely, they can do it better. Instead of being encouraged to challenge ourselves to the point that we run a real possibility of failure, every effort is made to ensure that this doesn't happen. In the process, we are denied the thrill of a hard-earned success.

Such negative messages about the capabilities of young people with disabilities can be countered by conscious efforts on the part of parents or other adults. As I was growing up, and to my complete consternation at the time, I was constantly challenged by my parents about whether I actually had done my best at different tasks. They attributed neither my successes nor my failures to my disability. In spite of what they may have felt inwardly, they never allowed me to feel that merely 'getting by' was good enough. While psychologists may debate the effects of such an upbringing on the young psyche, it did lead me to expect more of myself. Being challenged in this way also regularly required me to make choices for myself: I chose either to keep working at something to make it better, or I chose to declare the deed done.

The importance of receiving the message that those who care about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated. Having a 'good' failure is something everyone should experience. To know that it is a normal part of life and that people still care about you and believe in you can encourage you to get up and try again. Another effect of this kind of early learning is a sense of feeling more in control of your own destiny.

The more significant a person's disability is perceived to be, the more urgent it is that he or she be given every opportunity to exercise choices. Whether children with disabilities indicate their decisions through verbal communication, or with the aid of a pointer, a micro switch, or a communication board, it is important that they exercise the right to make choices, and in matters in which they can see the effects of their decisions.

3. Lack of Stable Support Systems

The lack of basic support systems to help one cope with failure can be particularly difficult for persons with disabilities. Discontinuity in some of the basic necessities of life, such as home, community, or friends, especially during the formative years, can add an additional barrier to the disabled person's freedom to make autonomous choices. In some cases, the person's need for security and safety in the environment may outweigh the benefits of assuming a new role in the community or taking on a new job that might further his or her career. While it may seem contradictory to the earlier point about overprotection, having a sense of belonging and a feeling of continuity in your environment is an important element in being able to challenge your capabilities. To be comfortable in taking risks, it helps to know that you've got a place to come home to after it's all over.

For parents, this means trying to provide stability and security for your children with disabilities to the greatest extent possible, while also giving them the freedom to explore. I believe that young adults with disabilities who are beginning to cope with increasing responsibilities and who are feeling overwhelmed by their choices can ease their anxiety by looking for small ways to bring stability to their world. For example, I love Mexican food, so at least once a week, even if the walls are crumbling around me, I go to the same familiar restaurant where they know me by name and always seem glad to see me. A small detail, perhaps, but it helps me gain perspective when other things are in flux. No matter how unstable an individuals's circumstances may be, being able to find even one small 'island of calm' that provides an anchor can do wonders for one's sense of stability.

I have listed three basic obstacles that young people with disabilities face as they strive to become adults with the confidence in their own capabilities necessary for exercising self-determination. All three barriers have the potential to limit opportunities in making choices. Parents can help their children to overcome these barriers by providing as many opportunities as possible that allow their children to take prudent risks and make decisions independently.

As I see it, there are two challenges to be addressed:

- o How to expose children with disabilities to more opportunities to make choices for themselves and to deal with the consequences of their choices; and
- o How to support and encourage young adults with disabilities as they explore their capabilities and options.

The answers that parents and other caregivers come up with today to these questions will determine the degree to which the next generation of young adults with disabilities is prepared to meet the challenges of a changing world. Ω

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SELF-DETERMINATION AND NORMALIZATION AMONG ADOLESCENTS:

The Family as a Crucible of Values

by Rita A. Varela

Parents play an important role in teaching their children decision-making and problem-solving skills. The family can be viewed as a "training ground" where members learn how to adjust to feedback from others, how to make decisions, and how to receive guidance in what is expected of them (Summers, 1986).

In the article that follows, the author discusses the family as a source of values and support.

Since 1983, Ms. Varela has worked as a programmer analyst for GTE Data Services in Tampa, Florida. Her latest breakthrough is a book on statistical analysis, Victory Over Statistics, *targeted to mid-level managers, MBA students, and grant writers. Before coming to GTE Data Services, Ms. Varela was a project coordinator for the American Coalition of Citizens with Disabilities in Washington, D.C.*

She was born and raised in New York City, where she attended public school, and received her undergraduate degree at City College of New York. She has an M.A. from New York University and is working on an M.B.A. from the University of Tampa.

Ms. Varela has cerebral palsy.

ntroduction

When I think about the term "self-determination," the overriding issue that comes to mind is the question of how to live your life in such a way as to actualize its full potential. I also associate the term with my days as a graduate student in political science, when the need to make a living and pay the rent was far from my thoughts and the diaries of libertarians such as John Stuart Mill and Henry David Thoreau absorbed me.

"Self-determination" is not a term I generally associate with rehabilitation literature. Yet, clearly, the term touches on two areas which are crucial to understanding both adolescents and disability: first, the role of the family as a crucible of values; second, the roadblocks facing disabled youth and the strategies families can follow to overcome them.

The Family as a Crucible of Values

Many authors have portrayed the family as a crucible of values from hich we learn about winning, losing, cooperation, and conflict. I subscribe to this view with joy and fervor.

It was from my family that I first learned about planning, persuasion, and money. I don't remember when I did not know that a nickel was worth more than a penney, a quarter was worth more than a dime, and paper money was what you saved in the bank so that you could buy a house on Long Island. As for planning and persuasion, I still remember the arguments I had with my folks whenever I wanted to go downtown by myself. I grew up in New York City and was unable to use public transportation, so before I asked permission to go anywhere, I would go through the long, drawn-out process of calling a van service, negotiating over a day, a time, and a price, and investigating all the other details I had to memorize in order to prove to Mom that I could be trusted to take charge of my destiny. As I look back on those days and the hazards of urban life, I realize that the most extraordinary part of the arguments was that I won them.

To an adolescent, self-determination means the power to run your life your way. It means the right to make all the choices that adults in society can make. Before we dismiss this definition as simplistic, let me suggest that it has one virtue: namely, it mirrors the experience of transition from adolescence to adulthood. Though cynics may quip that parents won't stop telling their children what to do until they reach the age when they forget who their children are, parents do let go. The torch -- which in this case is the power of young adults with disabilities to make choices that once were made for them -- is indeed passed in the vast majority of cases. With that torch come lessons. Planning, persuasion, and introductory economics involve basic cultural and political information transferred from parent to child so early that we rarely identify when a child begins to scheme, negotiate, or barter. This transfer nearly defines traditional parenting.

Roadblocks and Remedies

The motivation underlying this transfer is empowerment. Parents want their child to enter the world of adulthood on an equal footing with all other adults. People with disabilities, however, often face roadblocks to full equality. Many roadblocks are institutional. Others stem from personal conflicts over values and identity which invariably befuddle adolescents.

All advocates know about the institutional roadblocks. We've all heard about parents who fight to get their child in school, who literally beg to get a dentist to treat their child, or who spend hours on the phone tracking down reliable transportation. The remedy for these roadblocks is equally clear: parent advocacy -- which means fighting, fighting, and more fighting. Personal roadblocks, however, are more complex.

A persistant sore faced by youth with disabilities concerns the problem of putting disability in perspective. Where does the disability end and the "you" begin? When things happen to you that you don't like, how much can be ascribed to you as a person and how much to your disability? Most kids with disabilities feel they are overprotected. So do most nondisabled kids. The difference is that in the former case, the kid is plagued by the thought, "If I weren't disabled, would it be different?"

Parent-child conflicts are a fact of life, not just a fact of disability life.

Parent-child conflicts are a fact of life, not just a fact of disability life. Children with disabilities need to know that. They need to learn how the world works, how authority is transferred from parent to child, and how to get around obstacles. One of the best things parents can do to teach their children about the world is to widen the family's social circle. Though socializing is not always seen as either a priority or a simple matter by the parents of a child with a disability, teenagers with disabilities should see how other teenagers deal with their own conflicts with parents. Some teenagers with disabilities will conclude that the grass is greener in the next yard; others will not. In any event, a child can learn a lot by watching other children elbowing their way through adolescence. Parenthetically, watching other parents deal with teenagers can be instructive to grown-ups, as well.

An issue related to families and values concerns therapy on the homefront. More specifically, it involves the danger of parents becoming too focused on rehabilitating their child. Though I can't prove it scientifically, I firmly believe that the quality of your ethics, or, more precisely, the amount of time devoted to examining your ethical assumptions, bears directly on the quality of your life. I believe, for example, that all children should be taught it is wrong to steal apples. I do not feel that you should skip teaching this if your child hates apples or if your child is severely spastic, in a wheelchair, and unable to "reach" for an apple.

Though I do not advise parents to refuse to do therapy at home, I do suggest that parents set limits. The home must remain a home, not a rehab center. In that home, all children should be treated as future citizens, not as patients. And in that home, if a choice must be made between administering therapy and taking time to explain why it is wrong to steal, I urge the latter.

Summing Up

Perhaps the quintessential portrait of the family as a crucible of values occurs in *The Autobiography of John Stuart Mill* (1964). Mill describes taking long walks with his father and discussing famous books. His father used these occasions to offer "explanations and ideas respecting civilization, government [and] morality" (Mill, p. 29). That portrait sums up my view of what politics is all about, as well as my views of parenting at its best.

Self-determination? It means the right to make the kinds of choices that others have a right to make, and it requires equal access to public institutions. Parent advocacy? Parent advocates are the first in battle, tackling roadblocks which threaten a child's chances to participate in society and compete on an equal footing. The family? That's where you learn to plan and fight and scheme and dream about being the President of the United States. When you are a clumsy, sweaty, five-year-old, no one on earth will share those dreams with you except, possibly, your parents.

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ANGER IN YOUNG ADULTS WITH DISABILITIES

Society often does not allow an individual to forget his or her disability. As a result, many young people with disabilities feel frustrated and angry.

The section that follows is taken from a letter written by a young man to a counselor who expressed concern over a 7-year-old client's anger at having cerebral palsy. The author of the letter, who has cerebral palsy, is presently studying to be a lawyer.

Dear ______________,

...I would like to add my own observations based on my perspective as an adult with cerebral palsy who was once an angry 7-year-old. When you stop to think of it, the anger the child feels is not unreasonable. Adults tend to overlook the fact that being able to walk and talk properly is much more important to a 7-year-old's satisfaction with life than it is for an adult. It may seem very unfair to the child to have been singled out for this problem. Furthermore, the adults around the child seem powerless to correct the problem.

Indeed, the child's anger may be a reflection of the disappointment that the adults around feel. The anger may be self-directed. I'm guessing at this child's feelings, based on my own experience and those of other people I have known who have this condition. The important thing is that the anger is interfering with the child's development.

In your letter [to me], you talk about teaching the child to accept the disability. Frankly, I think the notion of acceptance is overrated. Many of the people I know who have cerebral palsy and who have succeeded in becoming independent and contributing members of society are quietly angry. The difference is that they've learned to use their anger in constructive ways.

Your priority challenge as a counselor may be to help this child channel the anger away from self and others and toward the challenges presented by the disability. It may help the child to know more about cerebral palsy and about people with cerebral palsy.

It's important that the child knows that there are people in this world who have as much and more difficulty with walking and still manage to lead satisfying lives. It would be even better if the child could meet some adults with cerebral palsy who are living in the community, and learn more about the activities that people with disabilities can enjoy (J. Murphy, [personal communication], June, 1987).

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TIM BECOMES AN EAGLE SCOUT

by Bud Fredericks

Having role models may be one way to dissipate some of the frustration, anxiety, anger, and lonliness that many young adults with disabilities feel. Role models need not be superheroes, but rather people with disabilities who have accomplished goals that are important to them.

The article that follows describes a young man whose determination has led him to realize personal aspirations that man[illegible]ever attain -- a strong sense of dignity and self-worth.

The author of this article, Bud Fredericks, is a research professor at the University of Oregon in Monmouth. He is the father of four grown children and is active in the Association for Retarded Citizens.

The following is an excerpt of an article from Exceptional Parent, Volume 17, No. 2, March, 1987. (Reprinted with permission from the author.)

Boy Scouts, Girl Scouts, Campfire, and similar groups for youth offer excellent opportunities for children with disabilities to participate in recreational activities with those who are not disabled. Often, in larger communities, separate units are established to accommodate those with disabilities. This is a story of what [illegible] happen when integration occurs. It is also the story of what happens when a person with disabilities speaks for himself.

On April 21, 1986, Tim Fredericks was awarded the rank of Eagle Scout in Troop 161, a regular Boy Scout Troop of Philomath, Ore. (population: 2,500). One of the guest speakers at that ceremony had the following to say:

> "The State of Oregon spends millions of dollars annually to maintain those with disabilities in separate work facilities and in institutions.
>
> This community demonstrates how to integrate someone who is disabled into the mainstream of its society. Troop 161 could be a model for all other Boy Scout troops."

Choosing a Project

Tim Fredericks has Down syndrome. Yet his entire Boy Scout ca[illegible] of eleven years was spent in regu[illegible] Cub Scout dens and a regular Boy Scout troop.

Tim met the [illegible]ents for the twenty-one merit badges necessary for the Eagle rank, but most important was his Eagle project, which he independently chose. His desire was to speak at school assemblies and tell other students what it is like to be disabled. Eagle projects must be approved by the Boy Scout district. In this case, the district was quite enthusiastic about the project's possibilities and wrote an encouraging response to Tim's request. The next step for Tim was to prepare the speech and write letters to school principals requesting the opportunity to speak.

Tim reads at about the third-grade level, and he prints anything he writes. He can neither read nor write cursive lettering, nor does he adequately compose and write at the same time. Therefore, Tim and his family developed a technique for all of his correspondence. Tim dictates what he wants to say while one of his parents prints his words. Tim then copies the dictated material. Tim's dictation over the years has become quite fluent, and he does not tolerate any editing of his ideas. He occasionally tolerates a suggested word or phrase change.

Writing a speech was more complex, however. Tim had many things he wanted to say to students who are not disabled and had no difficulty dictating these ideas over a period of two weeks. I suggested organizing the speech by subjects: school, work, friends, etc. Tim agreed, and all the ideas for each subject were grouped. Tim then added and deleted. Finally, a speech emerged.

The speech Tim gave was initially planned to be given to two or three high schools and junior high schools or elementary schools in the immediate area. He ended up by speaking twenty-seven times to more than 2,500 people. The speech he gave follows:

Tim's Speech

My name is Tim Fredericks. I am handicapped because I have Down syndrome. I was born with Down syndrome. Down syndrome people have an extra chromosome. Nobody knows why we have this extra chromosome. All of you have forty-six chromosomes. I have forty-seven. Would any of you like my extra chromosome? I would be glad to give it to you if I could.

I would like to tell you what it is like to be retarded. I am doing this so that you might be able to understand people like me.

School is a good place to learn, but I don't really like to go to school. I am a slow learner. I have a hard time spelling. Some of your teachers tell me that you have a hard time spelling, and you don't have my problem. I have trouble reading. Everyone tells me that I read about the fifth grade level. I hate to write letters and to write in my diary because it is hard for me to write.

After I graduate from school, I hope to live in an apartment with a good friend. I also hope to have two or three part-time jobs. I have two now that I get paid for. I work at Ark Animal Hospital every morning for two hours. I have to be there at 7:15. I work at Vandehey's Cabinet Shop three afternoons a week. I have been working now for more than a year at both jobs.

I do chores at home. I have to take care of all the animals, twelve chickens, three cats, a dog, three goldfish and a horse. That's a lot of mouths to feed.

I also help my Dad cut wood. I take care of my own room, and I help my Mom vacuum. She says I do a better job than she does. And she is right!

I love music, but I like hard rock best, but my Mom doesn't.

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I have a hard time explaining how I feel, but I feel the same way you do.

The hardest thing for me is when ople make fun of me or ignore me. or instance, I went to a dance a few weeks ago, and no girl would dance with me. Can you imagine how you would feel if that happened to you? Well, I feel the same way.

Kids on the bus used to make fun of me. That used to make me mad.

I have a girlfriend, but she goes to a different school than I do. I don't get to see her too often. She is handicapped too. I have other handicapped friends, but my best friends are Chris and Mark Weaver. They have been my friends for five years. I think they really like me, and I like them.

I feel good when people talk to me or are friendly to me. That's one of the things I like about Boy Scouts. The boys accept me as I am. They know I am handicapped, but it doesn't make any difference. I am a scout just like them. It takes me longer, and I have to work a little harder to get my merit badges, but I get them done.

That's one of the reasons I am here. I am trying to be an Eagle Scout. I ily have three more merit badges to go. My Eagle Scout project was to tell you about myself. I hope I have done that. I want to thank the principal, the staff, and students for letting me come and talk to you.

If anyone would like to ask any questions, I'll try to answer them, but if I can't, my Dad is here, and he can help me.

The Students' Reaction

And what was the reaction of the students? When he gave his speech to the school assembly of his own high school, the introduction by the principal was brief and noninformative: 'Tim Fredericks is going to tell us something about his Eagle Scout project.'

Tim stood before the student body of 400 with the microphone a little too close to his mouth so that his voice boomed throughout the auditorium. This was Tim's first speech, and so we as parents had little idea of what the reaction might be. The speech lasted approximately ten minutes. When he ished speaking, there was a spontaneous cheer from the student body, and all were on their feet applauding and cheering. Teachers were wiping tears from their eyes. One teacher said to Tim's mother, 'We all needed that. Thank you.'

Tim had been integrated into the high school for four years and had many friends who were not disabled, but the majority of the student body merely accepted him without really knowing much about him. However, after giving the speech, Tim said that everyone spoke to him.

Speaking to Elementary Students

It was fascinating to watch Tim give this speech, which was slightly edited from the one above, to elementary school students. The usual scenario went as follows: Tim would be introduced to approximately 100 students who would be sitting around the floor in a library or in some other general meeting room in the school. He would give his speech. At the conclusion of the speech, when he asked for questions, there would be a few seconds of silence followed by one hand of a student braver than the others. The question was usually quite simple. "What is your favorite music?" Tim would answer, and two more hands would be raised. Twenty minutes later, after a continuous give and take during a question period, half the student body would have their hands raised wanting to know more about Tim and what it is like to be handicapped.

We do not know the full effect Tim has had by being his own spokesperson, although many people have shared their personal reactions with us. We do believe he has made many more students and adults aware of the competencies that people with disabilities can have, and that those with disabilities are, first and foremost, people.

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Suggestions for Parents: Helping Children Achieve Self-Determination

Being aware of the significance of self-esteem and decision-making and problem-solving skills in a young person's overall development does not necessarily mean that parents and professionals know how to how to encourage the growth of these skills. The following suggestions for how parents and others can help children and young adults with disabilities develop a sense of self-worth and self-sufficiency have been developed from readings in disability literature and from conversations with individuals with disabilities.

- Treat your child with a disability as a capable human being by encouraging and supporting his or her efforts to explore, take healthy risks, and try out new situations.
- Provide opportunities for self-awareness by focusing on your child's strengths and the qualities that make him or her special and unique.
- Let your child know that you enjoy spending time with him or her. Try to really listen when your child shares thoughts and experiences with you.
- Share your family stories, histories, and traditions with your child to help the child understand that he or she is a member of a family circle, with a permanent place in the larger scheme of things.
- Provide opportunities for interaction with others of different ages and backgrounds to help your child develop social confidence.
- Help your child experience success by encouraging him or her to build on known strengths and abilities.
- Acknowledge your child's efforts toward a goal, not just the final product or accomplishment.
- Have realistic expectations; don't expect so much that your child is set up for failure or frustration, or so little that you communicate a lack of faith.
- Let your child take responsibility for his or her own actions.
- Acknowledge your child's presence. Include your child in discussions with family and friends. Don't interfere unnecessarily to answer questions that were directed at the child.

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- Give your child a chance to grow into a unique adult. Avoid using labels such as "shy," "lazy," or "clumsy" to describe your child.
- Respect your child's need for privacy and time alone. Don't intrude unless it is absolutely necessary.
- Promote your child's assertive (not aggressive) behavior as well as respect for others. Being assertive is an excellent way for your child to avoid being exploited or taken advantage of.
- Encourage your child to practice and use basic coping statements to handle difficult emotions, such as anger, jealousy, or fear, but by all means, encourage their expression. (An example of a coping statement might be: "I can do this. I'll be just fine." or, "I really feel upset, but I need to stay calm.")
- Acknowledge your own sense of self-worth, when appropriate. Your healthy self-image will be a good model for your child.

There are many resources available to help parents understand their role in helping their child with disabilities learn to achieve self-determination. Many such resources are listed at the end of this *Transition Summary*.

As you face your responsibility as a parent, a teacher, or a professional in helping a child with disabilities achieve self-sufficiency, remember that learning to be independent is a difficult task for all young adults. Likewise, it is sometimes difficult to earnestly encourage a child's independence: letting go is one of the most difficult tasks that parents face. What is important to realize is that all children, regardless of their strengths or weaknesses, have to try many times -- and sometimes fail -- before they can gain the self-assurance and sense of personal worth that comes with adulthood.

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This document was developed by Interstate Research Associates, Inc. pursuant to Cooperative Agreement #G0087C3051 with the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

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NICHCY would like to thank our Project Officer, Helene Corradino, at the Office of Special Education Programs, Office of Special Education and Rehabilitative Services, U.S. Department of Education, for her time in reading and reviewing this document. We also would like to thank Jim Murphy for his valuable insight and support in developing this document.

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Magazines For and About People with Disabilities.

Disability Rag, Box 145, Louisville KY 40201. Phone (502) 459- 5343 [TDY]. (A bi-monthly publication written by people with disabilities that covers the whole spectrum of disability rights.)

Legislation to Watch: The Disability Rights Bill.

As of this publication, this bill is pending before the House and Senate. It is sponsored by Congressmen Major Owens (D-N.Y.), James Jeffords (R-Vt.), Tony Coelho (D-Calif), and Silvio Conte (R- Mass.), and Senators Tom Harkin (D-Iowa), and Lowell Weicker (R-Conn.).

If passed, this bill would give individuals with handicaps the same rights afforded the disadvantaged and other minority groups under other existing Civil Rights legislation. For more information, contact Bob Tate at (202) 226-7532.

ORGANIZATIONS

American Association of Disability Communicators, c/o National Organization on Disability, Suite 600, 910 16th St., N.W., Washington, DC 20006. (An organization concerned with disability issues and seeking improvement in disability communications. Publishes a quarterly newsletter, the AADC News.)

The Beach Center on Families and Disability. Contact Gary Brunk, The Beach Center on Families and Disability, The University of Kansas, Lawrence, KS 66045. Phone (913) 864-4950. (A federally funded national rehabilitation research and training center on families and disabilities. The purpose of the center's research, programs, and training is to advance the rights of people with disabilities at every age as well as the members of their families to have enduring and supporting relationships with each other in their homes, neighborhoods, and communities.)

The Disability Rights Center, 1346 Connecticut Avenue, N.W., Suite 1124, Washington, DC 20036. Phone (202) 223-3304. (A center established to advocate for the rights of all persons with disabilities. Publishes information on understanding disability, employment discrimination, and other topics. Write the center for a price list for the publications.)

The Disability Rights Education and Defense Fund (DREDF), 1616 P St., N.W., Suite 100, Washington, DC 036. Phone (202) 328-5185 Voice or TDD. (A national nonprofit organization run primarily by people with disabilities. Offers information on the civil rights of people with disabilities. Publishes *Disability Rights Review*, a quarterly newsletter.) The national office is located at 2212 6th St., Berkeley, CA 94710.

Mainstream, Inc. , 1030 15th St., N.W., Suite 1010, Washington, DC 20005. Phone (202) 898-0202. (A National non-profit organization that works with corporations, state, local, and federal government, educators, and rehabilitation professionals to move persons with disabilities into the workplace. The organization sponsors conferences and disseminates publications on employment.)

National Self-Help Clearinghouse, 25 West 43rd, Room 620, New York, NY, 10036. Phone (212) 642-2944 (A national information and referral service for people seeking or wanting to create a self-help group.)

People First International, P.O. Box 12642, Salem, OR 97309. Phone (503) 378-5136. (A self-advocacy group of teenagers and adults with developmental disabilities. People First exists in 20 states. Addresses and phone numbers of existing offices available through the Salem, OR address.

The Research and Training Center on Independent Living, BCR-3111 Haworth Hall, University of Kansas, Lawrence, KS 66045-2930. Phone (913) 864-4095 [Voice/TDD]. (A center established to help people with disabilities live more independent lives. Conducts research on issues in the independent living field. Produces materials from studies, research, and training activities.)

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Appendix L

Making Contributions

- Giving a massage
- Volunteering time
- Making a gift
- Pitching in recycling
- Sticking up for someone
- Helping someone move
- Doing someone a favor
- Helping with yard work
- Caring for children
- Hugging someone
- Sitting with someone who's sick
- Sewing or mending as a favor
- Helping with light housework
- Walking a neighbor's dog
- Doing community service
- Giving or sending flowers
- Offering help if someone needs it
- Helping a neighbor shovel snow
- Working on a political campaign
- Taking care of animals or plants
- Visiting someone in the hospital
- Lending books, tapes, or videos
- Holding the door open for someone
- Inviting a (new) neighbor over for dinner
- Running errands for someone else
- Lifting things with or for a neighbor
- Receiving packages for a neighbor
- Offering good thoughts or prayers
- Noticing or commenting on an improvement
- Watering someone's lawn while they're gone
- Assisting public broadcasting in fund-raising
- Spending time with someone who's lonely
- Giving somoeone a piece for their collection
- Driving somoeone to the doctor, store, etc.
- Remembering a special occasion, throwing a party
- Stopping by regularly to see how someone's doing

- Participating in a local park's beautification effort.
- Writing letters or placing phone calls to help out
- Ushering at an event or volunteering at a booth
- Asking if a friend needs something at the store
- Acknowledging someone's expertise, talents, or gifts
- Helping with small repairs around someone's house
- Admitting a repair or utility person for someone else
- Offering help finding needed numbers and resources
- Sending a card – thank you, valentine, birthday
- Cooking for others or packing a lunch for someone
- Offering friendship and support to someone having a bad day
- Passing along to someone else items no longer used
- Looking after a house or apartment while owners' are away
- Sharing news of a bargain, job, news item of interest to another
- Having a standing date for lunch with a friend at a local retirement home
- Taking a picture of someone in their setting or at a special event

Adapted with permission from New Hats, Inc., Salt Lake City, Utah.

Appendix M

Conversation Start-Up Kit

Ideas to assist people who have trouble knowing appropriate ways to strike up a conversation.

Riding on a Bus

Conversation with a stranger:

1 Does this bus stop at ——— Street? Thank you.

2 Pardon me. Could you tell me what time it is? (or some other information query)
Thanks. I was wondering if I'd be late for my appointment.

3 How do you like the weather today?
I like it *or* I don't like it because ——— .
I hope it changes tomorrow. *or*
I hope it stays the same tomorrow.

Conversation with someone you want to get to know better:

1 I sure like that ——— you have. I've been looking for something like that; where did you get it?

2 Would you mind if I sit by you? *or*
May I please sit by you? *or*
I'd like to sit here, would you mind?
(If no) Thanks, anyway. (smile)
Oh. Well then, I'll sit over here.

3 I noticed that you ride this bus every day. Do you enjoy it? *or*
Where do you get off the bus?

In a Store, Library, or Restaurant

Conversation with a stranger:

1 Do you know if there's a restroom here? (or a drinking fountain or a public telephone.) Thank you.

2 Do you know where the ——— are located? (example: *crackers*)
(Further description) You know, the kind that ——— .
I need them for ——— .

3 Could you help me with something? I need (or I want) to go upstairs, and I don't know where the escalator is.

(checking out or clarifying) Oh, do you mean. ——— ? *or*

I think I know what you mean; you mean *or*

Is this what you're saying? Is this the right direction?

Conversation with someone you want to know better:

1 Do you happen to know anything about ——— (a product)?

I'm trying to decide between ——— and ———, and I don't know which to choose.

2 Did you notice that oranges are on sale today? *or*

How do you like the new shopping carts?

(Examples: something unique or appealing or interesting, a change, a hot tip)

3 Do you know when this place closes?

Do you know if there's a bus stop (or a coffee shop) nearby?

At a Church, School, Social, or Sports Gathering

Conversation with a stranger:

1 Is there a ——— nearby?

- Drug store
- Bus stop
- Subway
- Pencil sharpener
- Coat room
- A coat rack

2 Is it OK if I ——— ?

- Sing loud
- Go in late
- Leave early
- Bring a guest
- Go dressed like this
- Don't have the right change
- Haven't got a ticket (or reservation)

3 Do you know where I can get a ——— ?

- Hymn book
- A drink
- Some popcorn
- Some refreshments
- Program

4 Would you mind showing me ——— ? (pointing it out) *or* Would you consider going there with me?

Conversation with someone you want to know better:

1 May I have a copy of ——— ? *or*
Is it OK if I copy ——— ?

- Your speech
- Your poem
- The article
- Your idea
- The instructions, directions
- The assignment
- The schedule
- Your map

2 Do you have ——— I could borrow? *or*
May I borrow ——— ?

- A pocket knife
- A pen/pencil
- A pad to write on
- A nickel, quarter
- Your binoculars
- A needle
- A flashlight
- Your book/tape

3 Could I have ——— ?

- Your telephone number, address
- Another chance
- Fifteen minutes or your time
- Your bracelet to look at (purse, ID card, ring, scarf, glove, briefcase)
- One of your flowers
- A tissue
- Some tape
- A paper clip

4 Would you be willing to share your ——— ?

- Bench
- Table
- Blanket
- Peanuts
- Popcorn
- Water
- Pew
- Program
- Sandwich
- Locker
- Newspaper
- Hand lotion

5 I'd like to ——— if that's OK with you.

- Save you a seat
- Call you sometime
- Come over to see you
- See you again

Adapted with permission from New Hats, Inc., Salt Lake City, Utah.

Appendix N
Additional Resource Ideas

Creating Community: A Catalogue of Ideas

- Organize a neighborhood yard sale, spring cleanup, or dump run.
- Participate in networks: weight watchers, ethnic associations, recovery groups, recycling centers, environmental groups, societies, volunteer organizations, political groups, watching or participating in athletics, fan clubs, big brother/sister.
- Fix up a house or yard.
- Create a community center, a playground, community recreation program, thrift store, flea market, community talk radio.
- Create or join groups/clubs: Hiking, biking, photography, book reading, horse riding, boating, sewing, pet or animal training, pottery making.
- Share the cost and use of land, a vacation home, condominium, RV.
- Become affiliated with a spiritual or religious group.
- Share catalogs and order things together: vitamins, sale catalog items, bulk foods, etc.
- Two households share cost and use of items: vacuum, bicycles, camping equipment, tools VCR machine.
- Create a slide show (or a series of slide shows) with individuals contributing slides from their own collections.
- Invite people over for: pancake breakfasts, games like charades or Pictionary , birthdays/celebrations/parties, open house, making Christmas cards or Valentines, Easter Egg decorating/hunt.
- Develop a lending library of books, tapes, records, videos.
- Exchange skills of a trade, craft, or hobby. Exchange services and skills with others: mentoring, apprenticeship, tutoring.
- Rent out things that you buy: bicycles, video machines, canners, juicers, etc.
- Do potluck dinners, barbecues.
- Make ice cream and have everybody bring ingredients for something to put on it.
- Attend self-help group meetings.
- Start or join a co-op: food, housing, child care, respite care, child-watch.
- Share a garden or agricultural project.

- Special projects: canning, food drying, making root beer/ sasparilla, baking Christmas cookies, fix-up projects, quilt making.
- Traveling and trips: zoo, special places, aviary, concerts, movies, camping, outings.
- Share rides or become part of a car pool.
- Assist in group efforts: community celebrations/ festivals, fund-raising events, disaster clean-up, sub for Santa, adopt-a-highway, neighborhood crime prevention.

Community Resources

Recreation and Leisure

- Golf course
- Movie theatre
- Novelty shop
- Parks
- Volleyball
- Riding stables
- Amusement parks
- Gyms
- Multi-purpose centers
- YWCA/YMCA
- Zoo
- Campsites
- Gardens
- Museums
- Ice cream parlors
- Television
- Art galleries
- Spectator sports
- Video rental
- Bowling alley
- Pools
- Planetarium
- Skating rinks
- Resorts
- Winter sports
- County recreation
- Game room or arcade games
- Local national & state parks
- Wilderness areas
- Photography
- Social circle
- Plays, concerts
- Water sports
- Picnic areas

Routine/Community Life

- Library
- City/county building
- Post office
- Buses, depots
- Airport
- Cabs
- Laundromat
- Motorcycles
- Public telephones
- Grocery store
- Fire station
- Police station
- Train stations
- Travel agencies
- Cars/carpools
- Bicycles
- Public restrooms
- Driver's license

Shelter, Money, Possessions

- Residential options
- Social services field offices
- Department stores
- Hardware stores
- Motels, hotels
- Malls
- Shoe store
- Thrift shops
- Convenience stores

Spirituality/Service

- Place of worship
- Nature
- News: TV and Radio
- Magazines
- Music
- Volunteer Organizations
- Newspapers, Books,

Work/Money

- Sheltered employment
- Job Service
- SSI office
- Community centers
- Department of Labor
- Banks
- Comnty. based employment
- Medicare/Medicaid office
- Vocational rehab office
- Credit unions

Physical/Biological

- Restaurants, coffee shops
- Food stamps
- Dental office
- Medical offices
- Barber, beauty shops
- Special equipment retailers
- Physical therapy
- Hospitals
- Spas
- Yoga/Aerobics
- Drug/alcohol abuse
- Meals on Wheels
- Community cafeteria
- Doctor's office
- Chiropractor
- American Red Cross
- Occupational therapy
- Clinics
- Alternative health care
- Rehabilitation
- Weight training
- Counselor, therapist

Rights

- Legal Center
- Mental Health Center
- Hospice
- Mental Retardation Assoc.
- DD Council
- Police
- Consumer groups
- Lawyer/Attorney
- Planned Parenthood
- National, state, & local Arcs
- Dept. of Social Services
- Legislative coalition
- Vocational rehab services
- Professional associations

Relationships: Friends, Family Social Life

- Dances
- Dates
- Clubs
- Relatives
- Agencies
- Parties
- Big Brother/Big Sister
- Neighbors
- Child care
- Counseling Center

Mental Stimulation

- Talking books
- Hobbies
- Respite care
- Community college
- Evening classes
- Personal interests
- Continuing education
- University

Adapted with permission from New Hats, Inc., Salt Lake City, Utah.

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